

WHISPERS AND SONG: A  
PHENOMENOLOGICAL INQUIRY TO  
DISCOVER NURSES' LIVED EXPERIENCE  
OF PERSON-CENTRED DEMENTIA CARE

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## **Whispers and Song: A Phenomenological Inquiry To Discover Nurses' Lived Experience Of Person-Centred Dementia Care**

Person-centred is now a widely used term to describe much dementia care in the UK and Jersey. This existential hermeneutic phenomenological research seeks to discover the lived experience of person-centred dementia care for nurses in Jersey and through this, the essences and meanings of person-centred care.

It is grounded in Merleau-Ponty's ideas of embodiment for being in the world and Buber's primacy of relationships and includes complimentary ideas within Lévinas, Gendlin and Vanier's philosophies. Its methodology is inspired predominantly by van Manen, it is hermeneutic in its interpretive and poetic stance and is existential in its focus on nurse's lived experiences.

Eight nurses, working in care homes and specialist dementia care units, took part in semi-structured interviews which were recorded and transcribed. Deep immersion into these texts followed using the six existentials of corporeality, relationality, temporality, spatiality, materiality and mood, proposed by van Manen and Todres, as lenses to get closer to the participants' lived experiences, essences and meaning of person-centred dementia care.

This research has been amongst the first to use six existentials for data analysis; it demonstrates the accessibility of this methodology for counsellors from its parallels with therapy; it demonstrates the potential of poetry and metaphor images to uncover the essences and meanings of phenomena; and its enhanced focus on the experience of person-centred care reveals considerable rhetoric in the use of the term in mission statements and care philosophies. This research shows that the term, and the models and frameworks associated with it, are not well understood, indicating the need to embrace a new understanding of person-centred care from the macro context to individual practitioners; the need for more effective training, education and practice development together with new support structures for nurses and better communication throughout the services. It also proposes a new vision focussed more on 'caring' than 'care' and for a uniting Jersey Dementia Strategy to help refine and define systems, policy, practice and care.

**Keywords:** Phenomenology, lived experience, person-centred dementia care, nurses, Jersey.

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### *List of Poems*

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### *List of Abbreviations*

ADLs	Activities of daily living
BACP	British Association for Counselling and Psychotherapy
BTEC 1-2	Business and Technology Education Council
CPN	Community psychiatric nurse
DNA	Deoxyribonucleic acid
DNR	Do not resuscitate
EHP	Existential hermeneutic phenomenology
ELC	Early Learning Centre
H&SC	Health and Social Care
H&SS	Health and Social Services
HCA	Health Care Assistant
HCP	Health care professional
IPA	Interpretative phenomenological analysis
JAA	Jersey Alzheimer's Association
JEP	Jersey Evening Post
MA	Master of Arts
NCS	National Counselling Society
PC	Person-centred
PCDC	Person-centred dementia care
PRN	Pro re nata (when needed)
QCF	Qualifications and Credit Framework
States	States of Jersey
TAE	Thinking at the Edge
WHO	World Health Organisation

### **Notes on the Art of Poetry**

I could never have dreamt that there were such goings-on  
in the world between the covers of books,  
such sandstorms and ice blasts of words,,,  
such staggering peace, such enormous laughter,  
such and so many blinding bright lights,, ,  
splashing all over the pages  
in a million bits and pieces  
all of which were words, words, words,  
and each of which were alive forever  
in its own delight and glory and oddity and light.

**Dylan Thomas (1914-1953)**  
(Thomas' own punctuation)

# Chapter 1

## In the Beginning: An Introduction



## Chapter One: Introduction

### In the Beginning

Not long ago I read one of the most beautifully written books I think I have ever read (*The Help* Stockett, 2010). It was a page-turner of the highest rank for me and left me no time, during its reading, to consider why this was so. I have since reflected on this and now know that I loved this book so much because it took me deep into the lives of so many people with whom I felt as though I had laughed and cried and felt deep raging anger. Yet, in reality, I had not met any of these people, but such was the author's commitment to write and the incredible power of her writing, I believed for a while I was truly immersed into, and part of their worlds. This was remarkable and I believe it changed me. But this was not all. I know now that it was not the book's subject matter itself, although of concern to me, that was what initially beckoned me in, but it was the hint that this was about a person who had been stirred by her own glimpses of others' experiences and then was passionate, even compelled it seemed, to listen to, and then tell the stories of those for whom she had become concerned. The final piece of the jigsaw fell into place when I realised that this very much reflected what was becoming clear to me as my growing passion to listen to and tell of others' stories.

This led quite easily to further reflection and when I asked myself what other books I had read of late and what films and television programmes I had watched and enjoyed in a similar way, I realized that I mostly choose to read and watch, and can be moved to tears, by real lifeworld stories in all their raw detail and ordinariness. I remember watching an episode of *24 Hours in A&E*, (16.1.2014, Channel 4) which perhaps most people watch for its gore and dramatic medical content, but I found it was the lovely, reflective and gently told stories of people's lives which truly captivated me. I thought this was excellent story-telling and an equally brilliant creative idea to tell these stories in this way. Perhaps the programme's designer knew it would be the drama and gore that would initially call the viewers to watch, but that it would be

these beautifully told stories of real life experiences that would keep viewers like me fixed to their seats. Stories are there to be told and we seem to want to listen, to engage and respond.

And this is why this thesis has come into being. I believe there are important stories to be told about the lived experience of person-centred dementia care, and with the telling, it is my hope that you will gain a similar sense of their importance, even if you yourself had never wondered about this subject matter in the first place. I hope that with the telling you will begin to wonder and to be changed. Wonder was the beginning for me. This led me to want to know what such care was like for those given the task of person-centred caring for people with dementia. This then seemed to me to intensify, so much so I could almost feel myself being pulled into a reverberating echo, or as Romanyshyn has described this, 'being addressed' (Romanyshyn, 2013 p. 348) by, and being called into something, the something I now know to be this research thesis. Romanyshyn, described such research as 'a 'complex vocation' in which 'the topic chooses you' and this more than 'you believe you choose it' (Ibid.) and Heidegger expressed similar ideas saying 'We never come to thoughts. They come to us.' (Heidegger, 1975 p. 6). Romanyshyn refers to this as unfinished business asking to be spoken and claiming its 'speakers' (Romanyshyn, 2013 p. 348). When I read this, I felt I could readily identify with Romanyshyn's words, but I was also feeling something like I imagine Moses must have felt as he was called to lead God's people out of slavery. He disputed this role with God himself and argued that his brother Aaron would be better suited to such a mighty task! God got his way, and although Moses did make some very significant mistakes along the way, he was indeed the person 'called' for the task (Good News Bible, Exodus 3-4). Likewise I was struck with the profundity of such a project and certain there were others better able to find the answers to the research questions that I posed in their own distinctive ways. This was even more poignant for me because, although my work takes me 'close' to nursing, I was extremely conscious that I did not share the same professional

background as the research participants and have no professional nursing experience whatsoever. Nevertheless, I could not deny my calling to this very complex vocation, and the 'answer' to this is what now fills the following pages. In van Manen's words I finally found myself in a place where, 'No encouragement is needed, because real courage has been ignited' (van Manen, 2006 p. 721) and I was able to trust Heidegger that,

'As soon as we have the thing before  
our eyes, and in our hearts an ear  
for the word, thinking prospers.' (Heidegger, 1975 p. 5)

### Beyond The Story Through The Gate Of Existential Hermeneutic Phenomenology

But my storytelling goes beyond that of a novel and deeper into people's lived experiences to find essences and meanings that may not be so evident only in a novel's telling. This research brings the spoken words, from the meeting of researcher and participant, through the gate of qualitative research, to a pathway illuminated by existential hermeneutic phenomenology. This goes beyond the objective world of some science and even beyond words, beyond distant observation and numbers and the testing of theory and hypotheses, and back to people and the world in which we live and have our being. These pages hold no graphs, no 'n' numbers and very few statistics; they hold people and the things of their worlds entwined together in the journey to new knowledge. This thesis is therefore existential and explicitly hermeneutic, acknowledging my presence, mingling and entwining itself within the lived experiences of the research participants.

Professionally I spend my days listening to others tell me of life as it is for them, how it affects them and often about the impact their lives have on others. These are private, confidential words that are the client's alone and stay between us, only occasionally being shared anonymously with my supervisor. In this research two things are quite different. Firstly, these stories have been offered for sharing by the research participants and

secondly, they have involved my voice in the telling, joined together with the participants' in a fusion of our horizons to describe and then intuit the essences and meaning of person-centred dementia care. This joint venture has involved me firstly in being with the participants and then in deep immersion into the transcribed texts. This was to attune myself to the whispered words, the silent music, and then the song, from behind the lines, underneath the words, around, above and below the spaces between the words, from the silences following pauses and sighs, and the powerful semaphore language of the body, to suggest even deeper meanings which may have been unsaid in plain words but quietly there alongside those that resounded more loudly and clearly (Merleau-Ponty, 1973 p. 43). Such is the nature of this deeply relational, embodied, worderly-dependant (van Manen, 1990, 2014), existential hermeneutic phenomenological project. From extensive literature searches (EThOS, UK PubMed/MEDLINE, Google, CINAHL, ProQuest, etc.) it became evident that this research would be amongst the first using this methodology and methods to discover lived experiences, essences and meanings of person-centred care for nurses.

### The Research Questions

This was a vast mission, which for clarity, I summarised in the following three research questions, which are followed by a summary of my aims and objectives for this thesis. The research questions are -

1. How do nurses experience person-centred dementia care?
2. What is the essence and meaning of their person-centred care?
3. How can an enhanced appreciation of the 'concrete everyday experiences of people be used more centrally to underpin care' (Galvin and Todres, 2013 p. 30) and thereby make a positive contribution to person-centred care in Jersey and elsewhere?

### The Aims and Objectives of the Research

1. The primary aim of this thesis, using van Manen's beautifully evocative language, has been to 'make contact' with you and 'touch

you' (van Manen, 2014 p. 373) and by so doing to bring you nearer to the essences and meanings of person-centred dementia care as experienced by nurses in Jersey. This phenomenological research does not therefore aim to present conclusive arguments, or offer new factual information about the phenomenon, but rather it 'aims to be allusive by orientating the reader reflectively to that region of lived experience where the phenomenon dwells in recognisable form' (Ibid. p. 390) or, as so beautifully described by Boye in her poem *Knowledge*, by immersion into the 'sea' of lived experiences (Boye, 1935).

2. It is a further aim of this research that having been brought 'nearer' to the phenomenon, your re-orientated gaze and its closer touch, might lead you onwards towards a newer experience of person-centred dementia care where you may feel as though you have been 'in conversation with' or immersed into others' experiences of it, and thereby 'see' it more clearly.
3. And finally, it has been my aim to attempt to stir up some 'wonder of the thingness of the thing' (van Manen, 2014 p. 52) in you, in the hope that this will impact in a positive way upon care for people with dementia by nurturing 'a measure of thoughtfulness and tact in our professions' (Ibid. p. 31), and 'take intersubjective understanding further' (Todres, 2007 p. 27). Todres is confident that such research can help to refine practice and help theorists clarify issues in debates, Finlay is confident that it can be of significance for policy makers (Finlay, 2011 p. 9) and Clarke, that 'context-specific', (2001 p. 101) 'local' research can change practice and challenge key concepts and values (Ibid. p. 103).

With such extensive aims, in the research context of Jersey, and with an existential hermeneutic phenomenological methodology, these have been the objectives.

1. To listen to nurses describe their lived experiences of person-centred dementia care through semi-structured interviews and to then explore essences and meanings beyond these descriptions.
2. To offer possible alternative interpretations by my immersion into and radical reflection upon the experiences themselves.
3. To present these findings in such a way that speaks the initial words, the whispers, songs and the silences between the words and the semaphore language of the body to a wider audience, turning to poetry where I have felt this could offer a means for further insight and reflection.
4. As I became more immersed in this research I began to wonder about the extent to which my professional training and experience was facilitating it. This led to a fourth objective which was to remain alert throughout the process to my lived experience of this methodology for the purpose of knowing if existential hermeneutic phenomenology would be an appropriate methodology to promote amongst other counsellors and psychotherapists, aware that this is only an emergent methodology in counselling and psychotherapy research and is still 'baffling' and 'strange' (Finlay, 2011 p. ix) for many.

Although the above may give the impression of a solid, inflexible structure, this existential hermeneutic phenomenological research is not separated, or as van Manen says more forcefully, 'severed' into method, the 'means by which results are obtained' and 'results', because the project in its entirety is the result (van Manen, 1990 p. 13) and has grown more organically. The thesis should therefore be read less like a textbook (which are not usually read cover to cover but more often delved into to find facts and figures or useful pieces of information) but more like a novel. All its parts are dependant and necessary for the whole, and although each has its subtle focus and style, they are all very intricately interconnected. Because of this, forming a structure in which to present the whole thesis was difficult and proved to be a very obvious chicken-and-egg scenario in which I could have chosen to order

some of the chapters differently. Finally however, I chose the order that just felt right for this thesis because, what became most important to me, as van Manen suggested, was the whole with its interrelated, interdependent, parts from the first words of its title to the very last word, read together for the full story to be told.

### Reflection and Reflexivity

Throughout this research, following my initial revealing of 'self' in chapter two, all subsequent stages of the thesis include personal reflections and reflexive engagement, the acknowledgement of my essential place and affect within it and of its effect on me. Existential hermeneutic phenomenology (EHP) welcomes the researcher's presence and interpretations, through the coloured lenses with which we see and experience the world, which affect, and thus add 'colour', to every part of the research. However, the extent to which the researcher is aware of this remains limited because there is always 'more' to ourselves than we know, with added shades to these lenses, colouring the deeply embedded depths of our being and silently taking their place (Todres, 2007 p. 44; Finlay, 2011 p. 23). Subsequent chapters focussing on the philosophical grounding of this thesis and its methodology develop these ideas further.

### The Use of Literature and Other Sources as Dialogical Partners

As well as my obvious presence as a voice, or dialogical partner, within this thesis contributing to the distinctive nature of it, a further distinction is found in the way I have engaged with other literature throughout the whole text and the vast array of sources I have included as other 'dialogical partner(s) to promote thinking' (Smythe and Spence, 2009). These include; novels and newspaper articles, lectures, academic papers and philosophical tomes, radio and television programs, film, music and others' poetry. My approach, also adopted by Paddy (2010) has therefore been one of seeing all literature and other creative sources as having the potential to provide significant

insights to be 'voiced'. These various voices will be present in varying depths, tones, and volume through this thesis, with for example, chapter 3 ringing loudly and clearly with the voices of writers on the subject of person-centred care and includes policy documents from Jersey adding their distinctiveness too. In chapter 4, philosophers have their say and affect, and in chapter 5 and 6 academic methodologist can be heard. A more resounding participant presence is clear in the first part of chapter 7, with mine more evident in the second part, though with the participants' there re-sounding 'within' my interpretations. Chapter 8 includes a true choir of voices, with mine perhaps taking the role of a cantor, the participant voices having initiated my singing and remaining implicitly present in mine, and with other researchers having their parts there too. Throughout the whole thesis are other voices of which you will be aware. These have also been dialogical partners influencing this research by shaping and colouring it along the way. They are the voices in songs, of poets, novelists, TV programs and documentary makers amongst others, without whom this project might look and sound quite different.

Furthermore, because I believe there is some incongruence with this methodology and a classical literature review, also supported by Smythe and Spence (2009), with these usually undertaken for the purpose of assessing what other research already exists in a particular field and then designing research to purposively fill the gaps with new knowledge, (McLeod, 2003 pp. 10-21; Smith et al., 2009 pp. 42-43; Finlay, 2011 pp. 184-186) I decided upon my alternative strategy.

This began with a search for other EHP projects focussed on person-centred dementia care for nurses, but as I found none within this narrow field, I widened my search. This led to other EHP projects that I read to develop an understanding of how other researchers had approached their projects. I followed this with a search for research related to nursing and dementia care not using EHP methodologies, some of the findings of which I have included



in chapter 8. My intention in this reading was to be informed, to allow it some creative space in me, and for it to be interwoven as appropriate throughout this thesis, but not for it to be reviewed as a separate part of this thesis. Therefore, after reading it, I put it aside to leave space for the creative development of my own project. My methodology confidently asserted that from its origins in open-ended wonder with due consideration of others' research and with welcomed insights from other varied sources to help locate, situate, illuminate, and the data to reverberate, I would come upon a new clearing emerging from the forests of my research field. I was greatly encouraged to pursue this venture and challenge the 'taken-for-granted way of the world' seeming to promote a style of literature review 'common across all methodologies' by Smythe and Spence (2009, 2012). These pioneer travellers have been great encouragers to me, both through their academic writing and their personal correspondence, along with Finlay and Evans who also cautioned researchers not be 'shaped too much by others' (Finlay and Evans, 2009 p. 74). From reflecting on this I crafted the following poem.

#### Fellow Travellers

Accompanying me along the way  
Have been others who have had a say.  
Great giants of the philosophical realms  
Have added their voices to those  
Well known for their methodological terms.  
These, entwined together in one accord  
Formed a mighty chorus that had to be heard.  
While others bellowed out their solo songs,  
Some whispered in gentler-voiced harmony,  
Their newer songs, reverberating, alive in me.  
Others hummed their presence into being  
And yet others, in their swaying, saying nothing  
Became known to me. And so,  
In shared camaraderie, we travelled.

## The Thesis Content

### Chapter 2

Because my research will inevitably have been coloured by my perception (Merleau-Ponty, 1945/1962) and my 'fore-understandings' (Gadamer, 1975/2013) I have followed this introduction with a chapter called *Who Am I?* This seemed the best way to continue as it describes my beliefs and values and my background and experiences all of which colour the research and this thesis throughout and have added to the 'calling echo' that led me into it. Placing this chapter here seemed natural, organic and almost inevitable, much like a bulb, which feeling the sun in spring, just has to grow.

### Chapter 3

Chapter 3 is an eclectic mix of background information, necessary for a fuller understanding of the context of this thesis. The chapter is divided into two main sections, focussing firstly on the former and current trends in thinking about dementia and particularly of person-centred dementia care, and then on the rather unique situation of Jersey in the Channel Islands in which the participants live and work. Initially I considered that the background chapter may be better placed immediately following this introductory chapter, but when I realized I was wrestling more with the need to present the thesis with an accurate chronology than a concern for its authenticity, my decision to position it as my third chapter was finalised and seemed right. Of course person-centred ideas and the research context of Jersey preceded me, but I believe the way I have understood these and presented them has been coloured or interpreted through my beliefs and values, my history and culture and by the extent of my knowledge of them.

### Chapter 4

Chapter 4 is dedicated to the philosophy underpinning this research. In this chapter I have described my whirlwind journey through philosophy in my search to discover the ground I needed in which to build the foundations of this research. This process naturally followed on from the more personal

reflections in Chapter 2. It continues with a section introducing phenomenology, and then describes existential hermeneutic phenomenology more precisely. It is followed by sections focussed on some of Martin Buber's (1878-1965) and Maurice Merleau-Ponty's (1908-1961) ideas, philosophers who have inspired me throughout this research, and also includes some complementary ideas of Emmanuel Lévinas (1906-1995) and the contemporary philosophers Eugene Gendlin (1926-) and Jean Vanier (1928-) who have left their marks on this thesis.

## Chapter 5

My attention in Chapter 5 is then focussed on existential hermeneutic phenomenology, the methodology that has catalysed this research into being. Selecting this methodology was critical and pivotal, as I believe this is what largely gives it its very distinct style and uniqueness, with its focus on the individual's experience of the phenomenon of person-centred care, and its interpretative and creative qualities. In this chapter I have described the fundamental principles, characteristics and assumptions of existential hermeneutic phenomenology: 'the theory behind the method' (van Manen, 1990 p. 27-28).

## Chapter 6

Chapter 6 describes the methods that I devised to set this research in motion, derived from its philosophical base and its methodology. This is very much concerned with the nuts and bolts of the project from its conception to its delivery, incorporating the planning and organisation of the fieldwork, including the way in which I have anonymised the data, the fieldwork itself, handling the transcripts, and then to the data analysis.

## Chapter 7

This leads into the Chapter 7 in which I present the data. Here you will hear the voices of the research participants describe their lived experiences of person-centred dementia care and my interpretative analysis of the texts to bring emergent essences and meanings to light, this by immersion into,

reflection upon, and working reflexively through the data. Although I have included some poetry in earlier chapters, to help develop my own and the readers' creative hermeneutic engagement and to extend the potential of the texts to speak in more varied tones and colours, I have depended upon this more in this chapter. Furthermore, I have also allowed metaphor its place offering alternative perspectives for understanding, and used punctuation and line spacing to help communicate the voice and tone of participants' lived experiences.

## Chapter 8

The penultimate chapter, Chapter 8, begins with a brief return to the origins of this research in the metaphor image (Lakoff, 1987; Romanyshyn, 2013) of *Wheelchair Man* and then looks at some of its potential limitations. Before offering a broader discussion of the research findings and what these may be saying more 'generally and typically' (Todres, 2007 p. 7) for person-centred nursing practice, I have developed a discussion of the philosophical tenets and the valuable perspectives they offered and followed this with a discussion of my methodology and methods and what these have added to existential hermeneutic phenomenological research and their contribution to counselling research. The chapter ends with a presentation of emergent new research questions and interests, inspired into being by this research, some of which it is my intention to pursue. The chapter therefore brings together my new perspective in existential hermeneutic phenomenological research and offers new insights on person-centred dementia care beyond that which has been formerly known.

## Chapter 9

The thesis concludes with Chapter 9. In this I have described my very personal and specific lived experience of my research journey, detailing what have been significant areas of growth and new learning. As with chapter 7, I have employed the lenses of the six existentials of relationality, spatiality, temporality, mood, materiality and corporeality for this reflection.

## The Intention In My Writing and the Quality Criteria for Existential Hermeneutic Phenomenological Research

Van Manen makes it quite clear that the intention of phenomenological research is 'a bringing to speech of something' (van Manen, 1990 p. 32) and that this is most commonly a writing and a rewriting activity. Romanyshyn calls for caution in such writing, appealing to researchers to ask the question, 'for whom is it being written', and stresses the need for research to 'find its proper voice' so that the end result does 'not loose touch with this feeling quality of our knowing' and that it should be research that 'keeps soul in mind' (Romanyshyn, 2013 p. 11). Romanyshyn's concern is that it may defeat its purpose if it is too academic and does not touch the soul of the writer in the writing and the reader in its reading.

The intention of EHP research is therefore quite unlike other research and for this reason should 'avoid trying to legitimate itself with validation criteria' from non-phenomenological methodologies (van Manen, 2014 p. 351), positions upheld by Etherington (2004 pp. 147-148), Finlay and Evans (2009 pp. 59-63), Finlay (2011 pp. 261-266). Instead they propose that such qualitative research should,

- Be based on valid phenomenological questions (van Manen, 2014 p. 350)
- Enrich our understanding of the human condition (Finlay and Evans, 2009 p. 61)
- Develop analysis derived from descriptive accounts of experience (van Manen, 2014 p. 350)
- Have aesthetic merit, using analysis to open up the text, inviting interpretive responses (Etherington, 2004 p. 148) that draw the readers in and make them feel 'touched by the findings' (Finlay and Evans, 2009 p. 62)
- Be artistically shaped, satisfying, complex and interesting (Etherington, 2004 p. 148)

- Be reflexive enough to make the author sufficiently visible, to enable readers to make judgements about the researcher's point of view, about the ethical issues involved, about how the information was gathered and which shows the researcher accountable to the standards required in telling others' stories (Etherington, 2004 p. 148)
- Impact the reader emotionally, intellectually and generate new questions or some other significant response (Ibid.)
- Evoke a sense of the lived world that seems truthful and credible (Finlay, 2011 p. 261).

It has been my intention to meet these substantial quality criteria throughout this research and for them to be evident within this thesis and that it should be more than just readable, that you will not be exhausted by facts or pinned down with explanations or imprisoned with ideas, but rather that its words will touch you and inspire you. With this in mind, I end this chapter with the following.

### So Now The Journey Begins

So now the journey begins-  
 Put aside, but never seek to abandon,  
 What you may already know and  
 Take with you only wide-eyed wonder,  
 Openness to the new in you  
 And what these worlds may hold.  
 Immerse yourself into them,  
 Be in the words,  
 The deepest sea - and listen-  
 With heart and mind and soul entwined,  
 With all that is you  
 And let your self be touched,  
 To experience, and maybe  
 Moved to change  
 By whispers and song.

## Chapter 2

Who am I? : My Beliefs and Values

## Chapter Two: My Beliefs and Values

### Who am I?: Introduction

Martin Buber (1878-1965) wrote that,

‘in order to arrive somewhere it is not enough to *go towards* something; one must also *proceed from* something.’ (Buber’s emphases, 1957/1974, p. 99)

This place Buber says cannot be a ‘standpoint’ but,

‘must be a real and primal ground: a primal reality that does not abandon me on my way to my goal.’

He qualifies this further writing,

‘It must be one that has produced me, and one that is ready, if I entrust myself to it, to bear me, to guard me, to educate me.’ (Ibid.)

While this thesis in its entirety is certainly my move *towards* answering my research questions and accomplishing its aims and objectives, the *from* is from me, my ‘*primal ground*’. This chapter therefore seeks to answer the question, Who am I? to reveal my *primal ground*, my ontological position, to which I have entrusted this research journey and thesis, as my ‘bearer’, my ‘guard’ and ‘educator’ throughout. Such attention to my beliefs and values, and the acknowledgment of my presence, my ‘intercorporeality’ (Merleau-Ponty, 1964 p. 168) and ‘my means of communication’ with the world (Merleau-Ponty, 1945/1962 p. 92) is essential to this existential hermeneutic phenomenological research. With this methodology researcher subjectivity is valued so that ‘rather than striving to be unbiased, distanced and detached, the researcher aims to be fully engaged, involved, interested in and open to what may appear.’ (Finlay, 2011 p. 23). While objectivity is not therefore the goal, the researcher still needs to attempt to put to one side, or reign in, pre-understandings informed by life history and life experiences, while at the same time engaging reflexively with their own subjectivity. This thesis is therefore an amalgam of the participants’ experiences and my subjective interpretation of these, for the purpose of looking more deeply to find new



and possibly previously hidden understandings of the phenomenon. This concept is developed in greater detail in chapter 5.

Who am I?  
Am I really what others tell me?  
Or am I only what I myself know of me?  
(Bonhoeffer, 1944 in Robertson, 2003 p. 38)

The words above are from one of the many poems written by Dietrich Bonhoeffer (1906-1945) while he was imprisoned in Germany for 'subversion of the armed forces' and shortly before he was executed in April 1945 (Robertson, 2003). In the poem he wrestles with this enormous question, which Guinness considers to be a haunting 'inescapable question of biography' (Guinness, 1998 p. 20) considering the opinions of others, together with his own self-analysis. The outcome of this is his clear conviction that, although he may never know the full answer himself, he is comforted to know he is perfectly and fully known to God (Ibid, p. 43). I have pondered this same question and in the process have been inspired by Bonhoeffer's struggle and moved by a song also entitled, *Who Am I?* In this, with the addition of a beautiful melody, the composer has engaged in self-reflection similar to Bonhoeffer's and comes to a similar answer in his closing lines.

'I am a flower quickly fading  
Here today and gone tomorrow  
A wave tossed in the ocean  
A vapour in the wind  
Still you hear me when I'm calling  
And you told me who I am  
I am yours  
I am yours  
(Casting Crowns, youtube.com)

Although I find both these to be very moving, a more powerfully emotive and beautifully crafted example of someone struggling to understand who they truly are, is I believe portrayed in the film *Les Misérables* based on the novel of the same name by Victor Hugo (Hugo, 1862/1994 and Universal Pictures, 2013). In this the central character Jean Valjean struggles to break free of

the past in which he was known only as Prisoner 24601, to continue his journey of becoming who he knows himself to be. But, he too wrestles with the question *Who am I?* and in time is able to say 'Who am I? I'm Jean Valjean' a man changed through time but still baring the scars of his past. As for Bonhoeffer, he too moved beyond seeing himself only as others did and claimed his name and identity.

In the early stages of this research journey I rather naively believed that I could answer this same question with no difficulty whatsoever and so, with some quiet confidence, set out to clarify my ontological position. As part of this process I thought it would be a potentially interesting project to ask others who knew me well, to tell me what they thought were my beliefs and values. What was offered back to me actually made me feel rather sad because, what I thought of as my many and varied beliefs and values, my lengthy 'creed' for life and my passion motivators, seemed to be condensed as rather curbed, token words. Others did not seem to know me as I knew myself. This chapter then became for me something of a personal journey of exploration and also perhaps a protest against those words. However, I was pulled up sharply even in the planning of this and before the first sentence was ever written. I had begun to understand how the esteemed Bonhoeffer and amazing character of Jean Valjean took so long to come to their answers.

### The Content of this Chapter

The following is my attempt to present the essence (van Manen, 1990 p. 32) of who I am. This chapter is divided into two main sections, the first of which is a summary of what I consider to be the drivers and influences in my life and the second concentrates on the outcome and effect of these in the beliefs and values I hold which have shaped and coloured my research and this thesis. Within each of these sections are subsections, which although presented in this structured way, should nevertheless be treated as interrelated and interdependent, in line with the philosophy and methodology

of such research. I have also adopted the phenomenological idea of essence here, so I have included those aspects of myself in answer to the question who am I? that necessarily make me who I am and without which I would not be me.

## Background

I am the second of four children, born in 1959 in Essex and brought up in a family of high achievers, although I myself struggled at school until I was about 16. This was the same Roman Catholic convent school my mother and older sister before me attended. I underestimated my abilities in most things and was not ambitious. However, as education was considered important I worked extremely hard in my last two years at school, became increasingly more confident thus enabling me to go to university. I never considered myself to be academic but more of a practical carer. I therefore put away the ideas I had of careers in teaching and nursing and concentrated on parenthood.

Disaster struck when my marriage failed at a time when I was acutely ill. To survive and conceive of any future for my family, I then began to ask the question Who am I? probably for the first time in my life. This led me to further study and into the work I now do and made me reconsider every aspect of the Christian faith into which I had been born and which had been a constant presence throughout my adult life as the former wife of a Church of England clergyman.

## Work

As I began to wrestle with the answers I was getting to the who am I question, I began to see that most of my time since leaving university had been spent in various caring, listening and mostly voluntary roles which were good and rewarding, though perhaps swamped beneath self-doubt, insecurity and illness. Because of the absolute need to rebuild my life on the foundations I was recovering of myself and to provide financially for my family I began to retrain as a counsellor. This was initially a 1-year course

followed by 3½ more years of both person-centred and cognitive behavioural therapy training to gain more substantial professional qualifications and although I did start to practice during this training, it was certainly not a speedy way to financial security. However, during this time I began to feel a sense of coming into my own, becoming more me and perhaps for the first time in my life really felt a sense of something like natural buoyancy: I was swimming without a lifejacket and was enjoying the water.

This training incorporated significant amounts of placement work, one of these being in a team based in the psychiatric hospital in Jersey and specifically in two units in which there were people with dementia. Interestingly I had not chosen to pursue these placements but accepted them only because no one else was interested. I was aware of a sense amongst others that these were considered second-rate placements with few job prospects attached. I think perhaps, even at this point, my heart was beginning to warm to those with whom I would be working because of this sense that working with people with dementia and various mental health conditions was considered less important work by some. This seemed to tear at my belief in the equal value of all human life and perhaps even reinforced it. This was the first time I had ever worked with people with dementia so it was a relief to feel immediately comfortable in what I was doing. At about this time I happened to hear a sermon by the former Vicar-General of Harare, Zimbabwe, Reverend Canon Tim Neill, who not long before had to flee his homeland following increasing death threats to himself and his family. I remember his words touching me deeply. He said 'We are happiest and most peaceful when living out the deep values which are at the heart of who we are' (Neill, 2008). I knew then that this work was for me: it was therapeutic for me, it seemed to be affirming who I was, I was motivated and felt it to be something like a calling or a vocation. I thought this was too strong a word for a while, and even rather too religious, which I found I did not like, but nonetheless I felt it to be true.

During the early days of my employment as a counsellor and family support co-ordinator with Jersey Alzheimer's Association (JAA) I found I was missing the buzz of study so applied for and was accepted onto an MA in Counselling degree program. This incorporated a module entitled *Creative Thinking For Research: Thinking At The Edge*, a course which was to have a profound impact on my MA research and continues to impact this research thesis. Thinking At The Edge (TAE) is an extension of Eugene Gendlin's *Focussing*, (Gendlin, 2003 and Purton, 2007) which was already familiar to me from my counselling training, but this formalized 14-step program was new to me. It was developed by Gendlin with Mary Hendricks (Gendlin, 2004; Nou, 2004 and Claxton, 2006) to be applied in contexts other than counselling where new insight is wanted. It has humankind's creative nature at its roots, making use the ability of the body to *speak* from a *felt sense*, articulating new words formed from emotions, thinking and with the body, to enable what has been implicit to become explicit. Because I was increasingly concerned by what I was hearing of family carers' experiences I made this the subject of a TAE process but was initially quite shocked by its findings. The process gave the following implicit words their voice; '*advocate*', '*the silent voice of dementia given speech*' and '*shaking up the system*'. This soon became what I wanted to do and the MA research which followed (Wareing-Jones, 2012) sought to articulate the experiences of carers caring for a family member with dementia, motivated by my sense of being an advocate for people whose voice I believed could not be heard, for the purpose of shaking up the system, which I believed, from my work with families and people with dementia, needed some revision.

When this was nearing completion I was asked to join a group of various health-care professionals to input into the redesign process of Jersey's health and social services. At the end of one of these lengthy sessions a very senior employee approached me and with desperation in her voice said "Sian, why, oh why, do we have all these planning meetings and all this talk of gold standard person-centred care and yet we cannot get the person out

of the wheelchair?” Her words were powerfully delivered. I thought I understood her meaning, but I knew exactly what this meant for me. My observation of person-centred care in Jersey did not seem to reflect much of my person-centred counselling work and training and yet I considered that, because they were rooted in similar soil, there should be more similarities. I then wanted to find out how others, especially nurses, experienced person-centred dementia care.

In the early stages of this PhD process I was challenged to examine my very reasons for doing this research and knew that I had to decide if I could put aside these powerful motivators, or whether I should acknowledge these and then attempt to be open to the new from the research data, working reflexively with my own experiences and opinions of person-centred dementia care in Jersey throughout the process. The first seemed easy in theory, but for me practically impossible. The second seemed almost impossible, but honest. I chose the latter path and so began this most demanding episode.

As well as my family and cultural background and then my person-centred counselling training and my observations from my work with people with dementia that I have already described above, I am also very aware that my Christian faith plays its part in shaping who I am and how I see and experience and understand the world around me. Further to this I know too that I have been, and continue to be influenced by others whose literature I consider to have powerful messages for me in the world I love. The next two paragraphs will therefore take up these two themes of faith and others’ influences on me.

## Faith

From my first weeks of life attending church in my mother’s arms, I still continue to do so 57 years on. This has been a constant journey of faith, which has taken its twists and turns along the way. My faith is personal and

profound to me, dependant on what I experience as a living relationship with Jesus, rather than just the dictates of a church or doctrine. I am an active member of a local church, though this is very different from the Catholic church in which I grew up. I study the Bible and read a considerable amount of other Christian literature. I believe myself to be a 'liberal' and find that so much of the philosophical literature I have been reading more recently is very congruent with my faith. This in itself has been a considerable encouragement throughout this research journey. I have found most of the ideas of Martin Buber (1878-1965) Emmanuel Lévinas (1906-1995) Maurice Merleau-Ponty (1908-1961) and Eugene Gendlin (1926-) to be both inspirational and affirming throughout this process and have found that they do not seem to conflict very often with my own. Further to this I have found that the contemporary philosophy of Jean Vanier (1928-) seems to add sense and clarity to these in its practical application in L'Arche communities worldwide (Vanier, 1988, 1992, 1999, 2001, 2005, 2008 and 2013). I know that my faith influences my beliefs and values concerning, personhood, relationships, equality, alterity, embodiment, caring and about the place of science in the world. These are all subjects I address in the second part of this chapter. Before this however I need to conclude this section with a paragraph dedicated to the other writers and thinkers who I know have influenced me. These are numerous and seem to be an ever-growing number, with no doubt many more whose influence I do not yet appreciate and cannot name.

### Important Others

I have no doubt that Carl Rogers' (1902-1987) and Eugene Gendlin's (1926-) writings are amongst some of the most powerful influences on me and direct, not only my work, but have also changed the way I relate to other people in other contexts too (Rogers, 1951, 1961/2004, 1980 and Gendlin, 1978/2003, 1992, 1996, 2004). Others, including Viktor Frankl (1905-1997) with his ideas concerning purpose and meaning have shaped my own thinking on this subject (Frankl, 1959/2004); Mahatma Ghandi (1869-1948) and Martin

Luther King Jr.'s (1929-1968) different but equally radical calls for reform both personal and societal inspire me; Ernst Friedrich Schumacher's (1911-1977) *Small Is Beautiful: The Study Of Economics As If People Mattered* (Schumacher, 1973) oozes sense for the world for me; C.S. Lewis' (1898-1963) metaphors inspire and warm my heart (Lewis, 1953/1997, 1955/1998, 1966); Henri Nouwen's (1932-1996) writing is heart-full and heart-warming (Nouwen, 1976/1990, 1979/1994, 1981/1990, 1990, 1992/1994, 1994, 1996/1990 Mogabgab (Ed.) 2011) and Jean Vanier's (1928-) writings, and he personally since meeting him in 2014, is someone I want to emulate in his kindness, profound wisdom and radically different ways of being with people with disabilities. Only since beginning this research process have I ever been, to my knowledge, inspired by philosophers but now I can quite easily add those I have mentioned earlier to this list. They continue to be great teachers and reformers for me. Alongside these I must add the writings of Max van Manen (1942-) and Les Todres (1953-) whose finely crafted words have helped set me off on the path of existential hermeneutic phenomenology as a research methodology with some sense of illumination and hope for the final destination for this thesis (van Manen, 1990, 2007, 2014; Todres, 2007; Galvin and Todres, 2013). And finally, I am very aware of the powerful influences of hundreds of poets, especially when their words are combined with melody, to both break and mend me, heart, body, soul and mind entwined.

#### Who Would I Be?

Who would I be  
Without thee  
Oh words and  
Melody combined?  
A song to lift  
And one to break  
Me down, where,  
In the depths  
I find myself  
And in your heights  
The divine.



I see my background, my history, my culture, my age, my education, my faith, my work, and the many people who have walked into my life, either in person or through their written words, to be the coloured lenses of my experience of this world. They have co-constituted me and continue to work in me and are indeed very welcome guests in this thesis. But of themselves all these have no active voice: they make no sound. Instead they find this through their sculpturing, honing work on my beliefs and values, giving every aspect of my life, this research thesis included, its authentic colour, shape and voice. I will now give more particular attention to these.

### Beliefs Concerning Personhood

Before I can discuss anything else I need firstly to draw attention to my use of the word *person* and the words *human being(s)*. Like Allen and Coleman (2006 p. 210) I believe all human beings are persons, becoming so 'by being born of human parents' and therefore for me the terms are interchangeable, with the use of the latter being perhaps more appropriate in more technical or scientific applications. So, while there is much discussion of what constitutes personhood (Baldwin and Capstick, 2007 pp. 173-187; Dewing, 2008 pp. 1-6; McCormack and McCance, 2010 pp. 5-14) ranging from the possession of certain qualities or attributes (Brock, 1993) to relational aspects, the possession of a human body or a status bestowed by others, (Kitwood, 1997 p. 8) my belief is that a human being is a person.

Augustine's philosophy (354-430) developed the idea of people as 'created beings' (Clark, 1994/2001 p. 41) in the 'temporal realm' (Ibid. p. 34-35) making his reference the early Christian scriptures. Aquinas (1225-1274) developed these ideas of human persons being distinguished more by their likeness to the image of God than by their difference to animals, and by their capacity for relationships with each other and God (Kretzmann and Stump, 1993 p. 33). This thread is found in Buber's philosophy of people as relational beings with each other and with God in shared common humanity (Buber, 1947/2002 p. 243-244) and in Lévinas who says that it is in responding to the Face of the Other that we become human (Lévinas,

1961/1969). While Merleau-Ponty does not refer to a creator God in his philosophy, his definition of people as 'flesh of the world' also resonates with me. Therefore, like the ethicist Stephen Post (1951-) I take a pragmatic position on personhood, with people having a shared flesh-of-the-world identity and an absolute moral and spiritual entitlement, and thus avoiding what both Post and I believe to be others', including Kitwood's, messy definitions (Post, 1995, 2006). Post qualifies this by saying that a human being's worth is 'not in relation to social value, productivity and rationality, but in relation to some presence in the universe perceived as greater than ourselves' (Post, 1995 p. 31). I believe personhood therefore does not depend upon a status offered by anyone else, nor on anyone else's judgement of cognitive ability or physical strength but on our shared origins as people created by God from the same 'earth' source (Geneses 1.26; Runcorn, 2001) as 'universal flesh' (Merleau-Ponty, 1964/1968 p. 137).

So, who am I? I believe I am the person whom I have always been from my conception, and the same who is now certainly not in any way recognisable as the baby in my mother's arms in the photos taken in 1959. I am that person, but changed beyond all recognition. Like Jean Valjean I have changed my name along the way and this, no doubt, has changed others' perceptions of me, and maybe how I see myself, but I am still me, and I believe I will continue to be me as I maybe get a little greyer, or if one day I have dementia and do not remember my name.

I can explain this a little differently by considering another film character, Superman. In this story Clark Kent undergoes changes to such an extent that he becomes unrecognisable to others, even being given another name while remaining fully aware that he is Clark. Superman's abilities and contributions to the world are immense and he is loved and cheered on by all. In contrast, Clark's contributions seem negligible and he is often an object of ridicule. But, Superman and Clark are indeed the same person. Superman and Clark could never be seen together, in the same room at the same time, because

they share the same body. At his death there will be one body, in a coffin with one name-plaque, marked 'Clark Kent, a really super man'.

And so it will be with my coffin one day. There will, most likely, be a plaque reading 'Sian Wareing-Jones 14.07.1959- but only my first names and the reclaimed Jones in my surname will identify me as the baby my mother named, the remains of my embodied self bearing the scars of time. It will be me in there, created and known by God I believe, and possibly remembered by others as, Sian, my wife, Mum.

### Related Ideas of Death and the Body

I have found it interesting to observe the care and gentleness with which many nurses care for the bodies of people who have died. There seems to be respect for the dead, for personhood, which goes unquestioned beyond the grave. It seems too that in death ownership continues to some extent, as we refer to 'X's body, or we may go to Y's grave. Although I believe that death is the end of a person's life on earth (Genesis 3.19) and that we do not continue in some spiritual sense in the world, I relate to this respect and care continuing after the death of the human, physical body.

Sadly, as so often described in the media, such respect is not always so evident for the living. News reports regularly carry stories of poor care in care-homes (BBC, 11.12.2011; 22.02.2012; 26.02.2013; 02.06.2014) and I too have seen care that has fallen short of the care I have witnessed for the dead. I wonder why this is so. My heart has broken, and I have been angered hearing people referred to as 'this one' or spoken to as a child or punished by exclusion. This has affected me, and no doubt this research, cutting deeply into so many of my beliefs about personhood and the values by which I try to live and work.

## Beliefs Concerning Life

I believe that people are at the heart of God's plan for creation and that the transcendence to which Post referred (Post, 1995 p. 31) is born from God's creation of 'man in his own image' (Genesis 1.26) and of being filled with his breath or spirit (Genesis 2.7). This speaks to me of the equality of all human life, not dependant upon the judgements of others or on any disfigurement of mind or body, but on God's design, in which 'The very essence of the person is the image of God' (St John of Kronstadt, in Cantley, 2001 p. 66). While there are those who discredit people of faith through their criticism of these Bible stories, these were obviously not written as scientific documents, but rather as theological documents to teach of mono-theism to counteract the contemporary ideas of poly-theists. At 'Adam's' creation he was distinctly human and endowed with personhood, though I also believe that as we journey through life our natural tendency is to grow, and therefore there is a sense of becoming more oneself through time (Rogers, 1961/2004; Vanier, 1999/2012). I find evidence for this in that when most pregnant women talk about their baby, they are clearly relating to them as a person and someone they are getting to know. And on this subject my heart is warmed every time I hear the penultimate song in the film *Les Misérables* and the words 'to love another person is to see the face of God' (*Les Misérables*, 2013).

## Related Beliefs Concerning Embodiment

On a doorway into Chartres Cathedral in France there is a most beautiful carving depicting the creation of Adam, which to me speaks eloquently of the intertwining of body and the world from the very beginning of time. It shows God reaching down to the ground and from the earth around him is forming Adam. The scene is fixed at this point with tenderness and relationship clearly caught between man and God and the world (Runcorn, 2001, and Appendix A). In this I see the source of Augustine's philosophy of people as 'created beings' (Clark, 1994/2001 p. 41) of spirit and body (Ibid. p. 29) and Aquinas' development of this, describing people as 'single material substances' (Kretzmann and Stump, 1993). Merleau-Ponty's ideas of

embodied being in the world and universal flesh, relate in part to this earth/human synthesis, and Buber's ideas of relationships with others, with God and the world seem resonant with this sculptor's ideas (Buber, 1937/1953; Merleau-Ponty, 1945/1962). This sculpture describes almost perfectly, my holistic, non-dualist, relational ontology, which is so very different from Descartes' (1596-1650) and other modern philosophers including Karl Popper (Popper and Eccles, 1977). Instead, the phenomenological position I take relinquishes any 'polarities of mind-body, self-other, individual-social, feelings-thoughts, body-soul, nature-nurture, mental-physical, subject-object' (Finlay 2011 p. 21). So, with Augustine and Aquinas and Merleau-Ponty, I understand people, as embodied beings of the world, rather than as having bodies in the world. I believe that 'without my body, I would not exist' and that 'Existence realizes itself in the body' (Merleau-Ponty, 1945/1962; Gordon, 2013 p. 2) and that we '*are* a soul; we don't *have* a soul' (Major's emphases, Major, 2014 p. 141).

Interestingly at work I have often heard comments relating to this, suggesting beliefs quite different to my own, which are perhaps more in line with Kitwood's focus on the mind. I have heard both relatives and staff saying for example "This isn't the person I married" and "There's nothing left of him but this shell" or "This isn't Jo". When I hear such comments I hear myself saying, though to myself, "Well *who* is in the bed then?" Having just watched the film *Iris* about Iris Murdoch, it is clear that not everyone shares such beliefs. For John, Iris' husband, although dementia changed Iris from the vibrant lady she was in her youth, she remained the same love of his life. Should I develop dementia I hope that 'I' will not be dismissed from the room while others tend to 'the' body. These concerns are real for me and needed consideration as I listened to nurses talk to me about 'person'-centred care.

### The Primacy of the Relational

Relationships are right at the heart of Christian theology. God's relationship with 'Adam' is evident even while he is in the making and is soon followed by

the creation of 'Eve' the 'companion' for Adam because 'it is not good for the man to live alone' (Genesis 2.18). Throughout the New Testament Jesus seeks out the company of others, develops close friendships and commissions us to do the same. In art, many paintings, if not a portrait or landscape, will capture more than one person and from a small project I undertook in 2013, which I called *The Facebook Project*, most people's pages included photographs of themselves with others. The fact that Facebook even exists indicates to me that most people seek out relationships, necessary I believe, for people to thrive. My professional work is grounded on the notion of the therapeutic relationship developed by Carl Rogers (Rogers, 1980; Sanders, 2006) who was greatly influenced by Martin Buber's philosophy, the power of which I experience constantly in my work. Further to this I have experienced at first hand the restorative power of relationships in the lives of people who live and work in L'Arche communities in both France and England. Jean Vanier, their founder, was also greatly influenced by Martin Buber and Carl Rogers, with these communities built on the belief that relationships are not only therapeutic, but also a means for growth. These are places where Post's philosophy of care and love being 'not the technologically invasive "doing to" but the attentive "being with"' (Post, 2000 p. 3) is beautifully evident and I believe is some of the best care in action I have ever witnessed.

Literature and music are full with stories that speak of the power and the need for relationships. These can touch my heart because my experience of this is so real. To end this section I am quoting some of the words of one such song, *Soul to Soul*.

'Everyone needs someone to turn to...  
We all need a friend we can cry to...  
All I need is a friend I can talk to soul to soul...  
I'm feeling stronger now, so much stronger now...  
Soul to soul.'  
(Emperors of the Soul, The Temptations, 1989)

Merleau-Ponty's *Phenomenology of Perception* (1945/1962) is packed full of insight and wisdom on many subjects, yet he chose to end this 456 page marathon with this simple quote 'Man is but a network of relationships, and these alone matter to him' (de Saint-Exupery in Merleau-Ponty, 1945/1962 p. 456). Like The Temptations and Merleau-Ponty I too believe that relationships are essential for personal growth and well-being, but with these comes a commission to care which I explore in the following section.

### Care for Others

The rootedness of Christianity in Judaism with its core conviction that something holy and precious dwells in every person, still underpins the law and moral guidelines of our Western culture, protecting the person from violation. In this, humanity's ethic of care for the weak and the outcast is evident. This is my belief, which is not only a product of my cultural background but is also something I choose to believe for the direction of my life, holding onto Micah's words that,

'This is what the Lord requires of us – to act justly, to love mercy and to walk humbly with your God' (Micah, 6.8)

and, Jesus' statement that 'What you do for the least of these, you do for me' (Matthew 25.40). I find these powerfully motivating as Jesus' life was dedicated to caring and pointed us towards a way to care. However, while the foundations for this ethic of care may have been sure in the past, I wonder if this ground is now not so appropriate for a modern ethic of care, given Christianity is less dominant. Charles Taylor has voiced similar concerns for the future, stating that whatever inclusive moral sense of 'all humanity' we now retain, we may not be able to do so indefinitely' (Taylor, in Post p. 31). This came to light for me recently when reading that the international 'Great Ape Project' is seeking to imbue non-human primates with attributes of legal personhood and the Defence Advanced Research Projects Agency is pushing the limits of human-machine interfaces in an attempt to create better persons (Berg, 2007).

This theme of care for others was taken up in the recent letter from the House of Bishops entitled *Who Is My Neighbour?* written to the people and parishes of the Church of England before the General Election 2015. In this they wrote,

‘There is a deep contradiction in the attitudes of a society which celebrates equality in principle yet treats some people, especially the poor and vulnerable as unwanted, unvalued and unnoticed’ (Church of England, 2015 p. 27).

A lovely song which highlights this for me is Esmeralda’s song in the Disney film *The Hunchback of Notre Dame* called *God Help The Outcast*. In this she pleads to God for the mercy that outcasts do not find on earth, seeing in God’s face some sense that he empathises. She wonders if he too has been an outcast. She sings,

‘I ask for nothing, I can get by  
But I know so many less lucky than I  
Please help my people, the poor and downtrod  
I thought we were all the children of God.’ (Disney Films, 1996)

My heart is warmed by such artistic representations of caring because I believe this shows humanity at its very best. It reminds me of other great pioneer ‘carers’ like William Wilberforce who found the expression of his faith and care for others through politics, working tirelessly for the abolition of the slave trade, and Elizabeth Fry, a Quaker who dedicated her life to caring for prisoners and the homeless and setting up London’s first night shelters, and others including Martin Luther King Jr., Archbishop Desmond Tutu, Mother Teresa, Mahatma Gandhi with his belief that ‘it is the good of all that counts’ (1970, p. 53) and Nelson Mandela, who were all champions of human rights and justice. They all believed, as I do, in the equal value of all in society and that everyone should have the opportunity to flourish. They all had a clear appreciation of human inter-relatedness and a responsibility towards others (Mawer in Sentamu, 2015 p. 234).



I found that these beliefs were clearly represented in the writings of Martin Buber who stated that 'the repeated failure to meet a person as Thou, and the imposition of an I-It model of relating' (Buber, 1937/1953) diminished human kind and society and were responsible for what Kitwood later termed 'malignant social psychology' (Kitwood, 1997 p. 89) and that with Buber's 'I-It, the word of separation, has been spoken' (Buber, 1937/1953 p. 23). Emanuel Lévinas (1906-1995) took up similar themes, preferring to think of philosophy as the 'wisdom of love' rather than the love of wisdom, with his traditional philosophical pursuit of knowledge secondary to his basic ethical concern for the 'Other'. For Lévinas it was in the face-to-face encounter that one recognised the transcendence and heteronomy of the other, which called for something other than a dutiful response. For him the 'interhuman' calls us into our alterity and gives us the freedom to understand another beyond the limits of our experience and stereotypes (Lévinas, 1961/1969 and 1991/2006). In his focus on alterity Lévinas diverges from Buber saying that in the face-to-face intersubjective encounter there is asymmetry, with the Other remaining an 'elusive stranger, an absolute and infinite Other' (Finlay, 2011 p. 61) who will never be fully known, but charges us to be open to the otherness of the Other. I found both Lévinas' and Buber's contributions particularly helpful in my face-to-face encounters with my research participants. I believed that I-Thou relationships could flourish between us but I also expected some sense of asymmetry and while I was seeking to enter their worlds through their rich descriptions of their lived experiences, I also expected some sense of mystery in the otherness of the Other.

This is most clearly expressed for me in another Disney film *Pocahontas*. In this Pocahontas compares her deep knowledge of her land with the limited knowledge of John, a well-travelled young man. She says to him,

You think the only people who are people  
Are the people who look and think like you  
But if you walk the footsteps of a stranger  
You'll learn things you never knew you never knew.'

(Disney Films, 1995)

Such openness to the Other in caring I-Thou relationships is I believe possible when we 'walk in the footsteps of a stranger' and when empathy is active. I have recently come to love the work of the composer Karl Jenkins (1944-) and in his *Stabat Mater* is the most beautiful expression of this in these words of the forth movement.

'Feeling all the grief and sorrow,  
we live life with grief and sorrow in our hearts and minds,  
with tears that wait to fall  
when sorrow in the world is more than we can truly bear.'  
(Jenkins, 2008)

This is powerful and may seem rather desperate, but I believe that in such, almost sacrificial movement towards the Other, reminiscent of 'Jesus' constant posture of embrace and welcome hospitality towards others' (Milbank, 2015) that there can also be great blessing. Bonhoeffer developed this idea in one of his letters from prison to his fiancé. He wrote,

'He that is blessed, is himself a blessing. Let us wish that for each other and be that to all those for whom we work and for whom we care. That someone should be a blessing to others is that greatest thing of all isn't it? Not just a helpmate, or a companion or a friend, but a blessing.' (Robertson, 1999 pp. 33-34)

Vanier writes with similar conviction saying,

'So many of us flee from people crying out in pain,  
people who are broken...  
not knowing that the light is shining  
in the poor, the weak the lonely and the oppressed.  
Or if we do not flee from suffering  
perhaps we revolt in anger,  
and this too, blinds us to the light of Jesus  
glowing in the people who are in pain.

These pages are to tell you,  
my brothers, my sisters,  
not to run away from people who are in pain,  
or who are broken,  
but to move towards them,  
to touch them.

Then you will find rising up within you the well of love  
springing from resurrection.’ (Vanier, 1998 p. 1)

I have quoted Vanier at length here because I wanted to retain something of what I believe is the simple beauty with which he writes. Such movement towards the other is certainly evident in L’Arche communities and is also central in Gary Prouty’s ‘Contact Work’ which encourages carers to move towards the other (Sanders, 2007) as in person-centred counselling.

### Wonder, Questioning and Making Sense

I consider myself a wondering wanderer. When I am out walking, whether it is in the countryside or along the coast, I will so often pause and look and be filled with the wonder of what is before me, and then the inevitable words ‘I wonder...’ will flow, with the wondering followed by a whole host of questions that pour into my mind. I seem to love what I do not know and am always excited by the multiple possibilities that can arise from the initial wondering. I am pleased that Confucius’ (551-479 BC) words would seem to value this attitude. He wrote ‘to know that you do not know – that is knowledge’ (in Schumacher, 1974 p. 76) and even Einstein (1879-1955) has been quoted as saying ‘imagination is greater than knowledge’. In his autobiography Charles Darwin (1809-1882) wrote that his mind was a machine for ‘grinding general laws out of large collections of facts’ but cautioned that this caused some atrophy in parts of his brain which he believed could be ‘injurious to intellect’ and even ‘moral character’ by ‘enfeebling the emotional part of nature’ (Darwin, 1958/1993). Husserl (1859-1938) shared these concerns and as a mathematician and philosopher was concerned that,

‘abstract, quantitative measures could forget the qualitative ground of which the numbers are about – this textured, embodied, experienced world of coloured trees, sparkling stars, alternative ways home, remembered seasons, happiness, joy, anguish and sadness.’  
(Husserl, in Galvin and Todres, 2013 p. 25)

Even without these warnings I am certain that knowledge is non-sense without all other human faculties involved, and further, I consider that it is

actually impossible to take humans out of any scientific 'equation'. I believe we are there, inseparably intertwined in our world and in our search for knowledge. Therefore, while I love the complexity of some mathematical problems, 'of weighing, measuring and putting things in test tubes' (Buechner, 1973 p. 86) and am constantly awe-struck by the insights people studying the natural sciences can offer, my epistemology has to include what Schumacher calls 'the centre', which for this research is my self as the researcher and my beliefs and values, the coloured lenses with which I will see and hear the participants' lived experiences. He says that,

'All subjects, no matter how specialised are connected with a centre; they are like rays emanating from a sun. The centre is constituted by our most basic convictions, by those ideas which really have the power to move us. In other words, the centre consists of metaphysics and ethics, of ideas that - whether we like it or not – transcend the world of facts.' (Schumacher, 1974 p. 77)

### In Summary

With much phenomenological research, a chapter such as this is not requisite because, although researcher subjectivity is acknowledged, researchers nevertheless attempt to put themselves and their influences to one side (Gadamer, 1975 pp. 268-269; Finlay, 2009a p. 18). However, because existential hermeneutic phenomenology research places the researcher, with their 'historically affected consciousness' (Gadamer, 1975/2013 p. 349), 'forestructures' (Heidegger, 1953/2010) and 'shadowy pre-understandings' (Crotty, 1998 p. 97) in the midst of their research, such a chapter is necessary. The researcher becomes an accepted part of the content, with the expectation that they will seep into, affect and colour everything from the first stirrings of wonder to every written word. The researcher's contribution is considered valuable, with rigour added by engaging in self-reflection and by working reflexively throughout the research. This chapter has therefore been written to clarify the beliefs and values I have brought into this research, thus enabling my words to more transparently convey my meanings.

While I have maintained the obligation that the words I have chosen to use are 'more about the work than about me' (Romanyshyn, 2013, p. 3) they will nevertheless be infused with my strong accent, and while the conclusions I have come to are mine, they most certainly have been 'guided by the reality of the text' (Buber, 1957/1974 p. 101). This is so even when I have turned to poetry and metaphor, accepted in such research to develop insight and further reflection from the reader (Etherington, 2004; Finlay, 2011; Higgs et al., 2011 and van Manen, 2014). Because this has been true from the initial seed planting motivation for this research, I have chosen to position this chapter immediately following the introduction to this thesis, with everything you read coming via me, as much in the detail of the more factual background chapter, as in Chapter 7 where my accent comes through very clearly amidst those of the participants' voices.

With this in mind I will close this chapter with the wonderfully simple words of C.S. Lewis who, while describing the creation of the mystical world of Narnia, appreciates that not everyone will 'see' the same detail, and therefore will not experience the same event. His explanation for this is,

'For what you see and hear depends a good deal on where you are standing: it also depends on what sort of person you are.' (Lewis, 1955/1998 p. 143)

From this chapter, which has been my answer to the question of who I am, it is my hope that you will now be able to appreciate 'what sort of person' I am and gain some perspective of this phenomenon from my 'ground'. The following chapter now offers some background detail to the research context, including the island of Jersey, of dementia and dementia care, which, through the process of this research are becoming a familiar homeland, a territory in which I feel I now 'belong' (Chacour, 1990).

## Chapter 3

### Packing for the Journey: Background to the Research



## Chapter Three: Background to the Research

### Packing for the Journey: Introduction

I expect you will probably know what it is like to prepare for a long journey or even something of an expedition, either for yourself or when helping someone else prepare for their adventure. Just a few years ago I remember packing up my youngest daughter's most precious and important worldly possessions for her move from Jersey to university in London. It was awful for me. Because Gabby is the youngest of my four children, I knew this meant the beginning of her adult journey away from me as my dependant child, and it was awful too because of all the packing. How we would fit two parents, an 18 year old and all her baggage, including her 'cello and guitar into the smallest of Hondas and make it with some breathing space to spare, across the Channel and the South of England to London I did not know. Even more perplexing was the 'filing system' we should use. Cases? Bags? Like with like, or just go for some sort of 3D tessellation for optimum capacity, just squashing the essential 18 year old teddy bear in with everything else? What was for sure was that some things just had to be in that car; they were essential for Gabby to make sense of her new life in London.

The purpose of this chapter is very much like packing the car with the varied essentials for the journey and the new life ahead. Its varied content will help make sense of the research context, so, included here are sections defining dementia, the history and changing culture of dementia care, the development of person-centred practice and some of the more recent trends in thinking. I have also included sections describing Jersey's unique geographical, political and judicial position and provided details of its demographics, the provision of medical and social care and learning and development opportunities for health care professionals, together with some reference to future plans for the development of health care in the island as outlined in a recent White Paper and other government reports (States of Jersey (SoJ) 2012a, 2012b, 2012c). Van Manen describes this aspect of a

research project as 'a laying open of the question' in which the study is grounded so that such knowledge can be examined for what it may contribute, with such detail necessary to erase possible 'glosses' which may 'overlay our understanding of the phenomenon' (van Manen, 1990 p. 34). I settled on this chapter's content therefore, after considering van Manen's words and in the light of my reflection on packing.

### Dementia in the News

Dementia is much talked about in the general media and has been called, amongst other things, an 'insidious pandemic' (Attwood, 2011) and The Prime Minister of Great Britain and Northern Ireland has called it a 'national crisis' (BBC News, 26.03.2012). These themes have been taken up by organisations and academics, with Alzheimer's Research UK (2014) writing of the 'shocking impact it has on us all' and Dementia Action Alliance (2011) calling it 'one of the greatest challenges facing our aging society'. In a letter from the Chief Executive of The Alzheimer's Society in England (22.04.2014) to its members, dementia was described as a 'cruel condition', which 'creep(s) up unnoticed' and then 'seems to take away all the things that people hold dear'. The Wellcome Trust (2010) call it the 'most significant health crisis of the 21<sup>st</sup> century' and the WHO (2012) call it a 'key public health concern'. Durgahee and Durgahee (2012) writing in The Nursing Times say that 'dementia care is a national crisis', Hughes, Louw and Sabat (2006) say that 'Dementia is a huge global problem' and Dewing (2008, p. 4) quotes Harriot's (2006) catastrophising view of ageing as a 'serious contemporary social issue'. Smith (1992, p. 51) writing more than 20 years ago, described dementia as 'the greatest evil to be avoided', the hoped for avoidance being obviously unsuccessful in the light of the more recent demographics and statistics.

It is possible that some members of the public may have escaped hearing these powerfully emotive statements but most people are likely to have some tacit ideas about dementia and how this can affect people. There will be



many more however who will have heard these statements and know much more of the substance behind these news items through their lived experiences as nurses caring for people with dementia, and others who know more from their own living experience of dementia. While Chapter 7 provides insight into professionals' lived experiences of person-centred dementia care, and reveals the essences and meanings of this, the purpose of the rest of this chapter is to provide information about the context of this research, of the field in which the research participants live and work.

## Defining Dementia

Because of the significant range of definitions of dementia, and because these have changed substantially over time, providing a definitive definition is difficult (Biernacki, 2007 p. 2). For this reason, and because of an apparent bio-medical emphasis in Jersey, I have included the World Health Organisation's (WHO, 1992) definition (favoured by Biernacki), Kitwood's definition, and then in line with this thesis' focus on lived experience, I have included definitions of dementia offered by people with dementia which I have crafted together into a poem entitled *Dementia Is...* These three indicate something of the diversity of definitions.

The WHO describe dementia as,

'A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is impairment of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. The cognitive impairments are usually accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.' (WHO, 1992)

Kitwood's very different definition of dementia focussed on its individual manifestation in a person, dependant upon; their personality (P), their biography (B), their physical health (H), their neurological impairment (NI) and the social psychology a person experiences related to their living environment (SP), variables he chose to express as the equation,

$$D = P + B + H + NI + SP$$

(Kitwood, 1996 in Baldwin and Capstick, 2007 p. 78)

And this is how people with dementia have described dementia,

### Dementia Is...

It's this forgetting...  
The time – when you've just been told it,  
Forgetting you've been told  
And forgetting you've already asked.

It's this not being sure...  
Of his name – when you know you should know  
And though he's older than he should be  
His face looks familiar.

It's these mixed up feeling...  
That's what makes me so – angry  
When I shouldn't be – so it's the guilt and sadness  
All mixed up with smiles.

It's this dullness...  
This fog that's in my head  
You see – that's fucking up my brain – again  
So I can't 'see' if it's a shoe or a sock.

It's this pretending...  
Having to make them think  
It's all OK – and you haven't forgotten – but  
You have – and it makes you so tired.

It's this being loved...  
When you didn't know they cared,  
And it's going for a swim now – when  
Before you never would have dared.

Although the definitions adopted by nurses will inevitably influence the nature of their caring, from the poem above it is clear that people with dementia are likely to have some difficulty with the activities of daily living and with relationships which may become more difficult. Because of this people with dementia usually require increasing levels of assistance and support as their illness progresses but with 'Solidarity, comfort, reassurance, and ethically

appropriate medical care' (Post, 2000 p. 4) people's wellbeing can be significantly enhanced.

Within the bio-medical paradigm dementia is usually classified in three stages, and in Jersey people with dementia are referred to as being in either early, middle or advanced stage dementia. In the more advanced stages people usually need some specialist care, either at home, in hospital or residential care (Kitwood, 1997 p. 21; Brooker, 2001 in Cantley p. 155). These stages are not usually specified by time-frames as these can vary greatly, for unknown or unquantifiable reasons, but which, according to Kitwood, may be related to the type of dementia a person has, their general medical health, personality, relationships or life history (Kitwood, 1997).

### Causes and Types of Dementia

The human brain is an 'enormously complex structure' (Cantley, 2001 p. 9) consisting of two basic components called grey and white matter. Grey matter is made up of neurones that communicate through complex chemical signals. These neurotransmitters are responsible for regulating behaviour, sleep, memory, and appetite. Supporting glial cells provide nutrients to the neurones and repair damage. This is important for brain function because, unlike other cells, neurones do not duplicate themselves so need such continuous maintenance. White matter is the connective material joining neurones in different parts of the brain to others in complex pathways. With such interrelatedness, neurones in one part of the brain influence the activity of those in other locations. Grey and white matter are organised into four lobes, which together are called the cerebral cortex with distinct regions having distinctive functions. Disease can affect only one part of the brain, sometimes contributing to specific symptoms, or can be more generalised with complex symptoms. The temporal lobes regulate mood and memory and the hippocampus further into the brain is the location for learning. The anterior temporal lobe is where language, understanding and meaning are located and the frontal lobes influence personality, speech, and behaviour.

The parietal lobes, slightly further back influence the perception of visual signals, space and self and influence a person's ability to co-ordinate motor tasks. The occipital lobes are at the back of the brain and process the incoming visual images. The cerebellum is at the base and back of the brain and controls movement, balance and posture and the mid brain and brainstem control some of our more basic functions such as appetite and sleep.

Because of the death of brain cells and the reduced connectivity and function, symptoms can sometimes indicate the parts of the brain affected, (Ibid. p. 10) which may be confirmed by brain scans, though these are not used routinely as presenting symptoms can be sufficient for a diagnosis (Whitehouse in Binstock et al., 1992 pp. 22-23). The diagnosis usually then indicates the nature and cause of the damage, which is usually one of five main types including combined dementias. These together constitute over 90% of all dementias, details of which are included in the following paragraphs.

### Types of Dementia

Medical models usually describe differences between different types of dementia with Alzheimer's disease being the most common, accounting for between 50-70% of all dementias. While the disease itself is now much better understood, why it occurs is still not well known apart from some minority of cases in early onset dementia where genetic inheritance is a known factor (Biernacki, 2007; Cantley, 2008). It usually begins with mild symptoms and progresses slowly as an abnormal protein in the brain called amyloid clumps together to form plaques, which affect the health of neurons. These affected neurons are then believed to affect tau, another protein which damages the structure of brain cells. The damage results in the brain being less able to convey messages essential for movement, problem solving and language. Short-term memory loss is usually the first symptom of Alzheimer's disease and is usually followed by more severe symptoms with speech and

language becoming more difficult and memory impairment more significant (Whitehouse, in Binstock et al., 1992, pp. 23-26). Because Alzheimer's accounts for such a large percentage of dementias, all participants in this research were caring for people diagnosed with Alzheimer's.

Vascular dementia accounts for approximately 25% of dementias being caused by a reduced blood supply to the brain that usually results in a more rapid onset. The blood supply may be reduced by strokes or transient ischaemic attacks, leading to multi-infarct dementia, which may be caused by hypertension, diabetes, raised blood lipids, smoking or a catastrophic event. This indicates that some reduction in its incidence may be possible by improvements in health and lifestyle changes (Biernacki, 2007 p. 8; Cantley, 2008 pp. 17-18).

Lewy body disease, most common in men, usually shares symptoms similar to Alzheimer's disease making a specific diagnosis more difficult. However, visual hallucinations, some temporary disturbance in consciousness, a shuffling gait, falls and fluctuating levels of cognition and functional ability are more common with this dementia. The fluctuations in a person's abilities are particularly significant for person-centred care, as carers need to be aware of changes in care needs even during the course of one day (Graham and Warner, 2009 pp. 22-24; Cantley, 2008 pp. 15-17).

Frontotemporal dementia accounts for about 2% of all dementias, though it is thought to account for about 20% of all early-onset dementias between the ages of 40-65 years. Only a minority of people the research participants care for will therefore have frontotemporal dementia. The usual presentation of this type of dementia, because of its location includes; changes in behaviour which can sometimes be quite dramatic, significant personality changes and problems with reasoning which may also include loss of normal social inhibitions, stubbornness, withdrawal and aggression (Biernacki, 2010 p. 10).

Some authorities suggest that 10% of all dementias may be related to alcohol acquired brain injury (Graham and Warner, 2009 p. 27) caused by heavy and prolonged consumption of alcohol, but because Jersey's levels of alcohol consumption are higher than the UK, (SoJ, 2013a) this figure may be higher in Jersey. Alcohol acquired brain injury usually has a sudden onset causing considerable confusion, with very disabling amnesia and often prevents people from being able to form new memories. It is however unusual for people with this type of dementia to experience many of the other symptoms associated with other types of dementia. It is thought to be the only dementia that is preventable.

While the participants in this research may be caring for people with a diagnosis of a specific dementia, others will have less specific diagnoses. In all care contexts that I have observed in Jersey, and in tune with person-centred care principles, while nurses will need to be aware of a person's diagnosis and while this diagnosis may relate to a person's symptoms, care in Jersey is not delivered in contexts determined by specific types of dementia. It is more usual for people with similar care needs, to be cared for together in specialised wards or homes.

### Prevalence of Dementia

Dementia is common and can affect anyone (Graham and Warner, 2009) and although it is predominantly a disorder of older people, its prevalence increasing with age, some people in their 30s have been diagnosed with dementia. At age 65, 2.5% of the UK population has dementia, about 10% of people aged over 75 will be affected, with the prevalence doubling in five years so that by age 85, 40% of the population will have dementia (Cantley, 2001 pp. 10-11). The figures for Jersey are similar with 1.43% (1,401) of the total population of 97,857 (2011 figures) with dementia rising to 45% of people over 90 (Alzheimer Europe, 2013 p. 95; SoJ, 2012b). People diagnosed with mild cognitive impairment are not included in these figures though this may be seen as an indicator for the future as the diagnosis

indicates changes in a person's memory, which may lead to dementia in approximately 30-40% of people. It defines memory impairment in people of any age beyond that which is the normal forgetfulness associated with ageing.

As the demographic shape of populations change with people living longer and with improvements in diagnostic techniques and with some reduction in the stigma of dementia, dementia is becoming more prevalent. There are now estimated to be over 820,000 people in the UK with dementia and of these, two-thirds live at home, three-quarters of people living in care-homes have dementia, and an estimated 25% of all hospital beds are occupied by people with dementia. These figures are expected to rise considerably to more than 1 million people with dementia in the UK before 2025 (DoH, 2013 and Alzheimer's Society, 2015).

### The Economic Cost of Dementia

The economic impact of this is huge, currently costing the UK an estimated £19bn a year, twice the cost of cancer, and more than heart disease and stroke and yet only 2.5% of the government's medical research budget is spent on dementia research, while a quarter is spent on cancer research (Alzheimer's Research UK, 2014). There are now estimated to be more than 35 million people with dementia worldwide with 4.6 million new cases each year and a new person diagnosed with dementia every second. While there are no such figures for Jersey, because our H&SS provision appears to be similar to that of the UK and our incidence figures and population demographics are similar, (SoJ, 2014) it is likely that our costs, as a percentage of the total H&SC budget, reflect those of the UK.

### Prevention, Treatment and Cures for Dementia

There is still no cure for dementia, and treatments are not suitable for all people, nor for every type of dementia. The treatments for memory loss and other cognitive symptoms work to a limited extent by increasing the levels of

acetylcholine (ACh) a chemical transmitter in the brain which enables better communication between nerve cells. Other drugs are used to treat symptoms if they become distressing, including depression, hallucinations, anxiety and delusions and aggression (Graham and Warner, 2009 p. 53). The prevention of, and cures for dementia are being researched, with a 50% increase in UK government funding for research to £66m in 2015 following the Dementia Summit meeting of the G8 in 2013 (DoH, 2014 and UK Dementia Challenge Group, 2014) and, because it is believed that healthy lifestyles can help reduce the risk of vascular dementia and certainly alcohol related dementia, (Graham and Warner, 2009 pp. 26-27) there are renewed efforts in both Jersey and the UK to promote healthier lifestyles (SoJ, 2008a, 2012b, 2014).

### The History of Dementia Care in Western Culture

The earliest recorded definition of dementia is from the late 1500s, giving a very different picture to the three definitions I have included above. Then, dementia was described as,

‘a passion of the mind, bereaving it of the light of understanding. When a man’s perceivance and understanding of all things is taken away.’  
(Hunter and Macalpine, 1963 in Biernacki, 2007 p. 15)

By the end of the 1700s the Oxford English Dictionary defined someone with dementia as ‘senseless, mad, foolish’ the word being derived from the Latin word demens. These definitions indicate that for centuries dementia was linked with other mental illness and therefore, most people with dementia were removed from society and housed in asylums and workhouses alongside ‘the mad, the deformed, beggars, witches and the flagrantly immoral’. This was in the cause of ‘efficiency’ and ‘rationality’ and even believed to be for the person’s safety (Kitwood and Benson, 1995) though the French historian Foucault described this as ‘bestialisation’ because in reality people were treated no better than animals (Foucault, 1965 in Kitwood and Benson, 1995 p. 7).



During the 1800s attitudes began to change with asylums being re-created as places of re-education and 'moralisation' (Ibid.). From the 1900s there were further changes as some medical scientists began to reclassify some conditions and non-conformity as disease, heralding a new phase of 'medicalization'. For the first time dementia was seen as distinct from mental illnesses such as depression, schizophrenia and mania and thought to be due to acquired brain damage. In their post-mortem studies scientists observed and described specific changes such as cortical atrophy, enlarged ventricles, softening of tissue and nerve cell death that were not evident in healthy brains. In 1907 Dr Alois Alzheimer described abnormal lesions he saw in the brain of one of his former patients who had symptoms of dementia and before long the term Alzheimer's disease was used to describe others with similar symptoms (Cantley, 2001 p. 8).

Throughout this period, until as recently as the 1950s, care in asylums for people with dementia was commonplace in the UK and Jersey. These were often overcrowded with beds in high demand (Murphy, 1991 p. 7) and with varying degrees of confinement and care, reflecting some of the changing attitudes and new medical knowledge (Thornicroft and Tansella, 2003; Rollin, 2003). Dementia remained aligned with psychiatry with a move to mental health services following this, but with functional illness often undertreated, or even avoided by GPs. Significant changes however began to be seen from the 1950s with admissions declining (Murphy, 1991 p. 9). Kitwood suggested that this was 'for reasons that are as much financial as humanistic' (Kitwood and Benson, 1995/2004 p. 7) while Biernacki seemed to disagree saying this was because there was a 'recognition of the ill-effects of the asylum system.' (Biernacki, 2007 p. 15). Certainly asylums were closing and more people began to be cared for in the community with support systems to meet their needs. Until as recently as the 1970s however, 'good care' prioritized people's physical needs, as described by Altschul and Simpson (1977). Although it would not be disputed today that it is essential to meet people's

physical needs, twenty-first century person-centred care certainly does not single this out as the 'primary concern' (Biernacki, 2007 p. 16).

Kitwood, a pioneer for a new understanding about dementia and dementia care, recognised that the earlier beliefs about dementia and the treatment of people with dementia, were still influencing modern care and that these were in part responsible for 'two contrasting cultures of care' (Kitwood, in Kitwood and Benson, 1995/2004 p. 7). He believed that,

'the uncertainty that so clearly marks the present time has come about, in part, because of the breaking up of the ways of dealing with the mentally infirm that were established over 300 years ago.' (Kitwood and Benson, 1995 p. 7).

Kitwood attributed the impetus for change, but with some reserve as to its effectiveness, as being due to multiple factors, a position later supported by Biernacki. She believed that, people of fame speaking about their diagnoses, the work of the Alzheimer's Society, the development of some drugs to help slow the progress of the disease and treat symptoms, changes in government policy, changes in nursing education, new research interest in dementia, and challenges to the medical model, demanding acknowledgement of all the factors which contribute towards a person's experience of dementia, to have been significant (Biernacki, 2007 pp. 21-36). While the significance of each factor remains unclear, the amalgamation of these most certainly formed the ground into which new trends in thinking about dementia began to grow.

### Concurrent Trends in Thinking

While it was evident that a growing interest in the psychological perspective gave rise to the new focus on person-centredness in dementia care, traditional psychological approaches continued to embrace biomedical models (Bond, in Cantley, 2001 p. 47). These seemed indomitable with 'the belief that through science and technology all human life would be improved' (Ibid. p. 45). However, because of the belief that the mind and body could be

treated separately, which is not usually possible, and because it understood bodies to be like machines which could be fixed, which clearly is not always possible, and because these explained disease only in objective biological terms with the belief that every disease has a cause, the result was the increasing absence of the subjective person. It was these weaknesses in the biomedical model that then prepared the ground for other ways of thinking to grow.

Included in these is the sociological model of dementia. This states that people with dementia interpret their unique experiences and the meaning of these in a temporal dimension, located in a framework including their life histories, material circumstances and their struggle for inclusion within their society (Bond, in Cantley, 2001 pp. 47-48). Central to this idea is that the disability experienced by a person with dementia is a result, not of their impairment, but by the way they are treated by society and through inclusion or exclusion from it (Downs, 2000 p. 369; NCCMH, 2007 pp. 70-71; Derbyshire C.C., 2013).

A political and economic context for care was promoted more recently for the radical reform of services for people with dementia, with Scotland leading on this, designing new services on principles of equity and justice, a radical movement away from the historically low level of political interest world-wide. As demographics in most developed countries are seeing increases in the aged population and with better diagnostic tools and the push for early or timely diagnoses, it is likely that this political and economic interest will grow (Innes, 2002 p. 483-499).

Alongside these are other trends in thinking, including viewing dementia as part of normal ageing, as a terminal condition and with spiritual explanations, but these have begun to decline largely because of the negative effects on peoples' wellbeing with increased stigmatisation and exclusion (Downs et al., in Hughes et al., 2006 pp. 235; Gove et al., 2016). Post's attention to the

meanings we attach to, and our understanding of personhood and selfhood, and how this impacts on the moral aspects of care seems to have inspired more interest with much more debate and research on this subject (Martin and Post, 1992; Sabat and Harre, 1992; Post, 2000; Sabat, 2002; Hughes et al., 2006; Dewing, 2008; McCormack and McCance, 2010 pp. 5-20).

### Personal Reflection

While the changing trends in thinking listed above and the factors in Biernacki's list will most certainly have had their influences upon the changes in the care of people with dementia, I found myself at this point, taking time to reflect upon Kitwood's words in the light of the EHP methodology I have used for this research. Essential to this is my belief that my culture, history, life experiences, education, religious beliefs and much more no doubt, are indelibly woven into my being whom I am. The fact that I often work in the shadow, quite literally, of Jersey's now mostly closed-up psychiatric hospital, which was, in many locals' living memory, the asylum, must have its effects on me. The asylum is a formidably huge, dark stone building which, if it casts its shadow over me, probably will do for others, including those who have been my research participants and whose 'vision' may be affected every time they look out of the window at work. A television documentary I watched recently called *Secrets From The Asylum* (ITV, 20/27.08.2014) came back to mind and once again I found myself welling up with the emotions I felt while watching it. It was full of personal heartbreak as those featured in it discovered more about their family members and the conditions in which they would have lived, of society's attitudes and some of the treatments they would have experienced. Some of these people had clear memories of their family member. This is living history, and like Kitwood, I too am sure this is still having its effects both for better and worse. He considered that personhood was a status accorded by others (Kitwood, 1997 p. 8; Dewing, 2008) and perhaps with this in mind, Biernacki challenges those of us who work with people with dementia to consider the possibility of some residual stigma where some part of us believes that people with dementia are slightly

less deserving of funding and services than the young, with much of their lives before them and who are able to contribute economically to society, (Biernacki, 2007 p. 19) a subject also taken up by Gove et al. (2016). As a personal response to this and from years of working alongside people with dementia, I wrote the following poem, simply called *Stigma*.

### Stigma

Once it was the Big C  
Locked away as though,  
Communicable at its mention,  
I may be infected.  
But now such fear  
Has flown, that naive  
Understanding replaced  
By a newer, more deadly  
Big D we dare not mention.  
That word now locked away,  
As those who once bore  
The stigma of it all,  
And maybe still do.

### The Development of Person-Centred Dementia Care

Soon after I began working with people with dementia and their carers, I had what some have called, the 'bible' of person-centred dementia care, Kitwood's (1997) *Dementia Reconsidered: The Person Comes First* thrust into my hands with the accompanying words "If you are interested in *more than working* with people with dementia, you *need* to read this book". I did so immediately and in a very short time it resembled what would be described, at best, on Amazon as 'used with some significant markings'. In truth it was so covered in high-lighted sections and with nearly every page having its corner turned over (which in effect ended up being of little practical use) I had to buy a new copy for the person who had lent me hers. This literary meeting with Kitwood marked the genesis of my work with people with dementia and their carers.

Biernacki suggests that in the 1970's, even with significant developments in research and then a new phase of psychosocial approaches developed in the 80s, changes in practice were slow and that it was only in the 1990's that Kitwood's work began to provide significant alternatives. He challenged the medical models, promoting his new theory of dementia and a new model for care (Biernacki, 2007 p. 41) with his term 'person-centred' very quickly becoming the short-hand term for other psychosocial approaches and the championing of human rights for people with dementia (Brooker, 2007 p. 15).

I believe Kitwood's ideas were inspired by the philosophy of Martin Buber (1878-1965) (Allen and Coleman, 2006 p. 209; Phinney et al., 2007 p. 175) and by the work of the psychotherapist and counsellor Carl Rogers (1902-1987) (Brooker, 2007 p. 14). Kitwood appears to have incorporated Buber's ideas of dialogical personalism (Buber, 1958 p. 11) into his practice, with the relationship between the care-giver and person with dementia being essential and the means by which one could understand the human experience of dementia (Hughes et al., 2006 p. 209). Rogers was the first to use the term 'client-centred', which later became 'person-centred' to describe his work in counselling and psychotherapy, the central features of his theory being the uniqueness and wholeness of a person, and the centrality of relationships for human flourishing. Kitwood's first publication incorporating this term with reference to dementia care, and seemingly reflecting these influences, is *Person to Person* (Kitwood and Bredin, 1991) (Brooker, 2007 p. 14). Many other publications followed, with most of his ideas up to that point incorporated in the *Dementia Reconsidered* mentioned above. Kitwood's beliefs in the importance of maintaining personhood, the need for an enriched model of dementia, the power of a malignant social psychology and striving to understand the world from the perspective of the person with dementia, were the concepts which underpinned his tentative theory of person-centredness. Although still the subject of considerable debate (McCance et al., 2011 p. 2) they have nevertheless remained the pillars on which most person-centred care now rests and on which new frameworks

and models are being built (Brooker, 2007 p. 16). However, although the term person-centred has become 'all-pervasive on the UK dementia care scene' (Brooker, 2004 p. 1; McCormack et al., 2010 p. 620) and 'increasingly familiar within health and social care at a global level' (McCance et al., 2011 p. 1) this remains a 'rich and evolving discussion' (Harding et al., 2015, p. 8) with 'no single definition' (Harding et al., Ibid. p. 5). Although it is considered that 'greater clarity is still required on what is meant by person-centredness' (Dewing, 2008 p. 3; Brooker, 2003 p. 216) the following have been proposed as its four key principles and as a definition.

1. Affording people dignity, respect and compassion
  2. Offering coordinated care, support or treatment
  3. Offering personalised care, support and treatment
  4. Being enabling
- (Collins et al., in Harding et al., 2015 p. 5)

'...An approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development.' (McCormack et al., 2015 p. 3)

### Recent Models and Frameworks for Practice

Whilst 'The inherent good of providing care within a philosophy of person-centredness is irrefutable' (McCormack and McCance, 2010 p. 1) it is also recognised that there is difficulty with translating the core concepts into everyday practice (McCormack and McCance, 2006 p. 477). It is therefore considered by some to be a 'fuzzy' concept (Gachoud et al., 2012 p. 484; Bensing, 2000 p. 21) and therefore 'one of the most difficult therapeutic approaches' (Mearns and Cooper, 2005 p. 159). However, it is because of its irrefutable value and the challenges of translating this into practice, that new models and frameworks have been developed from empirical research for the purpose of enhancing person-centred practice. From their differing

practice perspectives most models and frameworks are rooted in Rogerian psychotherapy (Rogers, 1961) and psychoanalytic and humanistic theory, (Brooker, 2004) all articulate the complexity of person-centred practice (McCormack, 2004 p. 36) and all make explicit the need for health care professionals to move beyond a focus on technical ability to engage in authentic caring practices in helping relationships. The literature in this field is complex with continuing debates over the definition of the term person-centredness with some authors using the term interchangeably with patient-centredness and relation-centredness. While I believe fundamentally 'the word 'person' captures those attributes that represent our humanness and the way in which we construct our life' (McCance et al., 2011 p. 3) including our moral values, how we express our beliefs, how we engage emotionally and about our relationships, what is of prime importance to this research, is discovering how the research participants experience person-centred care and how it contributes to their care of people with dementia in Jersey.

Although there have been many new models and frameworks derived from Kitwood's initial ideas, and others independently, I have included details of the three I have encountered most frequently in discussions about person-centredness in Jersey in recent years, and that are used successfully in other care contexts 'to operationalize person-centred care' (Venturato et al., 2011 p. 252). These are the VIPS Framework (Brooker, 2004, 2007) the Senses Framework (Nolan et al., 2004) and the Person-Centred Nursing Framework (McCormack and McCance, 2006, 2010, 2016 in print; McCance et al., 2011).

## VIPs

Brooker has been a major champion of person-centred care for many years and has promoted her version, like Kitwood before her, in the form of a simple equation to introduce complex ideas. This has become known as VIPS.

$$P C C = V + I + P + S$$



In this, V is *valuing* people with dementia and those caring for them. I is treating people as *individuals* and not by a diagnosis or as a group. P is the need to look at things from the *perspective* of the person with dementia and S is the need for the *social* environment in which the person lives to be positive. Brooker refers to the parts of the equation as 'elements' as they can exist by themselves and have equal status, but when brought together 'they define the powerful culture of a person-centred approach to care' (Brooker, 2007 p. 13). However, it was because she recognised that such care 'was not easy to understand or articulate' (Ibid. p. 12) that she chose, successfully I believe, to present it as simply as she did.

### Senses Framework

Nolan et al. (2004) share a similar passion to Brooker, but described their new framework as going 'beyond person-centred care'. Because they believed that the term 'person-centred' had become a 'watchword' for good practice and 'is not the panacea that it is held up to be' (Ibid. p. 46) they proposed a Senses Framework (Nolan et al., 2001, 2004) based on Tresolini et al.'s (1994) relationship-centred approach and Mulrooney's (1997) prerequisites, as more appropriate for enhancing the care of older people. While their starting point was an essential respect for personhood, their focus is on relationships and interdependence, moving away from focussing only on the person or patient and including relationships with colleagues and others involved in their patients' lives. They describe these relationships as 'reciprocal, complementary and symmetrical' where 'all participants are meaningfully involved' (Ibid. p. 47). However for such relationships to lead to care of the highest standard, they believe that the prerequisite of a positive predisposition towards caring is necessary. With disparate groups built into tight networks of relationships with such predispositions, they propose that a sense of security, belonging, continuity, purpose, achievement and significance will result (Nolan et al., 2004 pp. 49-52). While I prefer Lévinas' notion of asymmetry and alterity in relationships (Lévinas, 1961/1969,

1998/2006) I nevertheless find this framework fits my ontological stance well with its focus on the relational and interdependence.

### Person-Centred Nursing Framework

A third framework to have emerged more recently has been McCormack and McCance's Person-Centred Nursing Framework (2006, 2010, 2016) which was developed from previous empirical research by McCance et al. (2001), McCormack (2001, 2003) and McCance (2003). This comprises of five interrelated constructs (2016) depicted as a mandala, including: the macro context, prerequisites, the care environment, person-centred processes, and expected outcomes. For the outcomes to be achieved, all the other aspects need to be evident. The macro context includes; health and social care policy, strategic frameworks, workforce development, and strategic leadership. The prerequisites include; professional competence, interpersonal skills, commitment, clarity of beliefs and values, and knowing self. The care environment focuses on the context in which the care is delivered and person-centred processes focus on delivering care through a range of person-centred nursing activities focussed on the person of the patient. The outcomes include; good care experiences, involvement in care, feelings of well-being and the existence of a healthful culture (McCormack and McCance, 2016, Appendix J). While I find this framework complex, I believe its comprehensive quality depicts the complexity of person-centred care most clearly.

In 1995 Kitwood described the dawn of a 'new culture of dementia care' as a 'coming home' and a 'cause for joy and celebration' (Kitwood, 1995 p. 11). By 1997 he appeared to have been less optimistic adopting a more cautious tone. He said that structural change was necessary, new training and educational opportunities were needed, a move away from the idea of a 'market of care' was necessary, increased financing was needed to put the components of good practice in place and that most change was likely to be seen where 'deeply committed people' were championing such change

(Kitwood, 1997 pp. 141-143). In response to this 'gigantic' (Ibid.) task, deeply 'committed people' have been at the forefront of research in dementia and behind the design and promotion of the models and frameworks I have presented above. While Dewing is quite clear that such frameworks 'can never please everyone or anyone of us all the time' (Dewing, 2004 p. 42) these have certainly attempted to reduce the complexities of person-centredness and facilitate the process of change yet further. Although they are now well established and used throughout the UK to enhance practice, they are not taught in Jersey. This is significant because although aspects of this are included in the mission statements or care philosophies of all wards and care homes in Jersey caring for people with dementia, and staff are expected to be delivering person-centred care, these models and frameworks seem to be ignored in practice.

### Jersey: An Introduction to the Local Context

While it is true that Jersey resembles the UK in some ways, and that most of the trends seen in the UK eventually lap onto our shores some time after their causative event (much like a secondary tsunami after a primary earthquake) Jersey is nonetheless a very unique island, being described recently in *Environmental Health News* as a 'peculiar place' (Spear, 2014 p. 18).

This uniqueness, or peculiarity, is the reason for some of my caution in the wording of the last sentence of the previous section. When I arrived on its shores from England 22 years ago, I was immediately stuck by just how foreign and old-fashioned Jersey was. Street names were in French or Jèrriais (our local language), drivers slowed down and gave way to others (and still do) our house had never been locked in its history and was passed on to us with no key, and just about everybody seemed to know everybody else. Some things have changed in two decades but I am aware that newer arrivals, or 'blown-ins' as they are called by the born-and-breds, still comment upon our slower pace and find us to be behind their times.

## Geography and Politics

Jersey at 45 square miles is the largest of the Channel Islands located 100 miles off the south coast of England and 14 miles from France. Its population of 99,000 is located across the island within 12 municipal parishes with significantly greater density along the south coast and in the 'capital' St Helier. Parishes are administered through the offices of an elected Connétable and deal with civil matters and provide some local services. Most major services are located in St Helier, which is therefore a centre for employment with the finance industry now having replaced agriculture and tourism as the major employer. Only 50% of the population are Jersey born with most immigration from the UK (31%) and Europe. There are restrictions, known as 'qualifications' on living and working in Jersey, with most immigrants gaining their residential and employment status through their employment.

Jersey is a British Crown Dependency and therefore not part of the UK or the EU though is part of the British Isles. It is totally self-governing with its own legislature known as The States of Jersey, which is made up of 49 elected members and other non-elected members, with appointed ministers including a Health Minister and deputies (Hunt, 1998; SoJ, 2015). Although British, its physical separation from the UK and Jersey's independent status are important to this research. Jersey relies heavily on recruitment of staff from the UK for the delivery of its health care and these employees work in services designed locally and not always reflective of those in the UK.

## Health Care in Jersey

Because of its independence, Jersey is not part of the National Health Service though has some reciprocal agreements for health care for travellers to and from Jersey. Further to this, and because we do not have a threshold population to support some medical treatments locally, Jersey residents with complicated health conditions may be treated in either the UK or France. Otherwise all health care is located on island (SoJ, 2011 p. 4). Jersey has a

large general hospital, a second hospital in which some clinics, including the Memory Clinic and rehabilitation services are located, and a psychiatric hospital with some dementia care and assessment wards.

Locally paid taxes and social security payments cover the costs of most hospital treatment but charges are made for some hospital services, by GPs, nursing services including district nurses, dentistry and social care. Other private health care is available and many services are also provided by local charities. As part of its restructuring program (SoJ, 2012b p. 20) The States is now in the process of commissioning some of its established services and newer services with bids for these projects being invited from local organisations. Social Security administers Income Support for those on very low incomes and a new Long-Term Care Scheme has recently been established, partly financed by a new tax, to cover some long-term care costs in care homes or at home. This has been welcomed by most as it has established a cap on the total a person needs to pay in care costs and protects some personal financial assets.

Health and Social Services costs accounted for 27% of the total State's budget in 2013 but with some aspects of the White Paper (SoJ, 2012b) in the process of implementation and with plans being drafted for a new hospital, these costs will rise substantially. Staffing is a major cost within this with most medical and nursing staff coming from the UK. More recently (2014) degree courses in nursing and mental health nursing, delivered in partnership with Health's Education Centre and Chester University, have been established to train Jersey residents, thus providing an established source of locally trained labour. This is particularly important as recruitment and retention of staff from the UK is becoming increasingly difficult (SoJ, 2011; BBC Radio Jersey 22.03.2016). Of further significance are new training opportunities for HCAs with the addition of BTEC 1-3 and QCF Diploma courses available through the local College of Further and Higher Education (SoJ, 2015).

## Dementia Care in Jersey

In line with UK demographic trends, Jersey's population is described as ageing, with an associated increase in the number of people diagnosed with dementia, following UK statistics for the percentage number of people with dementia by age group. It is estimated that there were 1,401 people with dementia in Jersey in 2011, which represented 1.43% of the total population, which is expected to rise to 1,716 by 2020 and 3,167 by 2040 (Alzheimer's Europe, 2013; SoJ, 2012c). While The States, like the UK government, are developing services to enable more people to be cared for in their own homes, (Froggatt et al., 2009 p. 9; SoJ, 2011, 2012b) Jersey already has an 'unusually high' percentage living in care and nursing homes which is 'greater than anywhere else in the UK' (SoJ, 2008 p. 28) amounting to 140 per 1000 (2007 data) compared to the UK figure of 85 per 1000 of the population over 75.

Diagnoses are made both by GPs and specialist gerontologists based at a Memory Clinic with further support offered by a team of specialist nurses, community psychiatric nurses (CPNs) and social workers. Support for people with dementia and their carers is also available from Jersey Alzheimer's Association (JAA). Within the general hospital there is no designated dementia unit but people known to have dementia may be supported by visiting CPNs. There is a specialist dementia care ward at a smaller hospital and within a larger psychiatric hospital there are two wards specifically for the care of people with dementia who cannot be cared for at home or in residential homes. All these have recently undergone some modernisation. Across the island there are two States of Jersey care homes, two Parish care homes and other privately owned care homes with some nursing beds. An estimated 50% of all residents have dementia, with four of the private care homes having specialist dementia units. In line with the figures for all employees in our health service, most nurses, mental health nurses and HCAs are not Jersey born or educated. My eight research participants work

in seven of these locations and of these only one was born and trained in Jersey (Alzheimer's Europe, 2013; SoJ, 2013d, 2015).

In the recent Green and White Papers published by the States (2011, 2012b) the Health Minister stated that Jersey offered 'good services' (Ibid. p. 2) (though no research had been carried out to discover service users' opinions on this) and that more staff would be recruited for new services planned to meet the projected increase in the number of people with dementia. My own MA research (Wareing-Jones, 2012) at that time however showed that service users defined the starting position for change as far from 'good' so the adequacy of the new service provision could therefore be debateable as present needs seemed not to be being met adequately. While I am hopeful that this PhD research will achieve one of its aims in bringing new knowledge of the lived experiences of nurses' person-centred caring closer to the policy makers and service designers' awareness, particularly as there are significant problems with the recruitment and retention of staff in the island, (SoJ, 2012 p. 14; BBC Radio Jersey 22.03.2016) I am also hopeful that this research might reawaken interest in my earlier work and add further insight for health's re-design process in Jersey.

As suggested in the introduction to this section, Jersey usually finds itself a little behind the UK in many ways, not least in its health-care strategies and services. Although person-centred dementia care is now considered the gold standard of care across the UK and is written into national policy documents (NICE, 2006; DoH, 2009) training courses, care planning tools, job descriptions and protocols (Brooker, 2007 p. 11) it is still a relatively new concept in Jersey, first discussed following a presentation by Kitwood in Jersey in 1996, and only then more formally recognised in 2009 after a 'Cornerstones in Person-Centred Dementia Care' course by Bradford University and the establishment of a Champions of Person-Centred Care Group. This group, now currently inactive, and was then the only body promoting person-centred care in Jersey until JAA more recently took up the

baton and the Education Centre began to include aspects of this within some of its modules for some students. Although person-centred care is promoted in almost all new health literature in Jersey (SoJ, 2008, 2011a, 2012b, 2012c) this training is neither compulsory nor easily available. Furthermore, care home and home care staff cannot access this training and many appear to have had minimal, if any, person-centred training. This situation should change however when new draft legislation for the regulation of care comes into effect in the near future (SoJ, 2013c). To date Jersey does not have a dementia strategy, though following the Alzheimer's Europe conference in Glasgow (2014) members of JAA returned activity campaigning for this, in line with The Glasgow Declaration 2014, as a tangible product of that conference.

### [Back to the Packing](#)

So you will have seen how the content of this chapter has been much like that of the car. It has included the essentials for making sense of what follows, with my review of the development of the concept of person-centredness and how this relates to the unique research context of Jersey. Prior to this I gave attention to the journey that brought me into this research and of my beliefs and values that have coloured it throughout. In the following chapter I will continue with the ground-works for its continued growth by describing its philosophical foundations.

To conclude this chapter I have included the following quote I heard recently on BBC Radio Jersey. The head of the Education Department in the General Hospital was being interviewed about the new nursing degrees in Jersey. In response to the interviewer's suggestion that new students would need to be high achieving academics and highly trained technicians, she disagreed describing the characteristics of the students she was looking for by saying that the key to being a good nurse was 'being a good listener, a carer and being compassionate' (Mesney, 2014). I wondered if in these few words she



had described the essence of person-centred care but had also set the entry requirements for these courses at the very highest level.

## Chapter 4

With a Pair of Well-Worn Walking Boots  
(and other Survival Gear) for the Journey:  
The Philosophical Framework



## Chapter Four: The Philosophical Framework

### With a Pair of Well-Worn Walking Boots (and other survival gear) for the Journey: Introduction

‘Three dangers threaten thinking.

The good and thus wholesome  
danger is the nighness of the singing  
poet.

The evil and thus keenest danger is  
thinking itself. It must think  
against itself, which it can only  
seldom do.

The bad and thus muddled danger  
is philosophizing.’  
(Heidegger, 1971 p. 8)

I have chosen to start this chapter with these words of Heidegger (1889-1976) for their wit, their wisdom and the warnings they contain for me, as I consider myself something of a singing poet, a thinker and now about to write a chapter describing the philosophical framework for this research. I like the way Heidegger balances his thoughts about thinking, and his perhaps slightly tongue-in-cheek reflection on philosophy, or rather philosophizing. They contrast so profoundly with the following words of Hawking and Mlodinow which I now want to include because they help to make my starting point very clear: my delight in philosophy, which I consider to be very much ‘alive’, and my sadness that some scientists believe pure or theoretical science to be a higher, or even, only source of knowledge. While of course pure science has its place, so too does philosophy, both ontologically and epistemologically, along with human qualitative science in which this research is grounded. If you the reader are a philosopher, or in any way interested in philosophy, or a qualitative researcher yourself, you will understand why I have included such a quote here and take a very different stance.

‘How can we understand the world in which we find ourselves?’ What is the nature of reality?...Traditionally these are questions for

philosophy, but philosophy is dead. Philosophy has not kept up with modern developments in science, particularly physics. Scientists have become the bearers of the torch of discovery in our quest for knowledge.' (Hawking and Mlodinow, 2010 p. 13)

I disagree with these authors but at the same time have a profound respect for most scientists and believe our ever-growing scientific knowledge of this amazing world in which we all live is enriched, in part, by developments in science. This is not lip-service. My first degree is a B.Sc., of which I am extremely proud and some of my best time-out time is spent proof-reading my daughter's M.Sci. course-work and accompanying her on local geology field-work projects. I also work part-time as a maths teacher. You cannot be anything other than an enthusiastic scientist teaching maths! But I also believe that 'the facts' of any matter are not the end of the matter (Guinness, 2005 p. 110). Science has its place, but here I am concerned with human science, which respects philosophical questions and grows its methodology from these roots to find its answers.

To help explain my position a little clearer, I am including the following in contrast. I believe this offers a strikingly alternative perspective, and although taken quite obviously from fiction, I celebrate its alternative wisdom.

'Well, sir, if things are real, they're there all the time'.  
'Are they?' said the Professor; and Peter did not know quite what to say.' (Lewis, 1953/1997 p. 48)

I think this is a lovely introduction to philosophy for Peter. The Professor, in response to Peter's rather arrogant, or maybe naive statement, does not proceed to give him a science lesson heavy in physics as he could so easily have done, or offered bold statements based on his own experience of other worlds, but rather he chose to offer a question which allowed Peter time for his own reflection and the opportunity to experience something of the 'phenomenon' for himself. This is very resonant with Merleau-Ponty's (1908-1961) statement in the early pages of *Phenomenology of Perception* that 'true philosophy consists of re-learning to look at the world' (Merleau-Ponty, 1962 p. xxi) and Jager's ideas that by 'viewing the world in the mode of

contemplation and within the dynamics of encounter' we can be transported 'to a cosmic and festive world where things and beings are able to reveal themselves to self and other' (Jager, 2010 p. 67). Epistemologically we can come to know things to be true by differing means, but for Peter, it was only when he experienced Narnia himself, that he could say it was 'real'. The Professor knew that no amount of scientific evidence or reason could prove this to Peter, nor that any emotional outpourings of his younger sister could turn his emotional response into knowledge. Peter's lived experience of Narnia and all 'the things and beings' of that land was the means to knowledge for him.

Peter's journey into new lands reflects something of my own. Before beginning this research project, although I had recently completed a research Masters degree, I rather naively thought that a PhD was more about very refined research questions and an equally refined methodology and method encasing the whole, rather than having much relation to philosophy! However, from the early days of this research process I quickly became enthralled with the subject and have since discovered something of its changing landscapes and the wealth of what it has to offer as essential equipment for the researcher's journey and for the generation of knowledge and theory. Merleau-Ponty's words are true for me: philosophy has helped me re-learn to look at the world and having taken Buber's (1878-1965) 'infallible test' I know that in 'men', by which I mean people, I find something profound which is simply 'there' and nowhere else and in nothing else (Buber, 1974 p. 4). I love science. It has its place in the quest for knowledge, but I know it is not the fountain of all knowledge and wisdom. Now I know of a 'deeper magic' (Lewis, 1953/1997 p. 148) that had been hidden within me, but which, through this project has turned from its implicit realm to become a new song, which has taught me to look at the world from new and multiple perspectives. I can now look, not just with my mind but with my heart and soul and body entwined together, and by engaging with others in their lives I

know that new knowledge is quite near the horizon, ready to enrich my own understanding and others’.

### The Plan for this Chapter

In this chapter I aim to firstly summarize my rather extensive journey through the philosophical traditions preceding the phenomenologists, the intention of this journey being a search for confirmation that phenomenology would be congruent with my ontological and epistemological positions and that it could provide a methodology suited to my research questions and the means for answering these. There is then a section describing the earliest roots of phenomenology in the work Edmund Husserl (1859-1938) which is followed by a focus on the ideas of philosophers I have found to be very resonant with my own ideas, beliefs and values, themes which run throughout this research thesis and have given it its distinctive character and to which I return throughout. Philosophers of particular interest to me because they constitute the ground for my research are, Martin Buber (1878-1965) and Maurice Merleau-Ponty (1908-1961) (my walking boots) with some reference to Martin Heidegger (1889-1976) Hans-Georg Gadamer (1900-2002) Emmanuel Lévinas (1906-1995) and the contemporary philosophers Eugene Gendlin (1926-) and Jean Vanier (1928-) (the other survival gear). The chapter then concludes with a summary of the main tenets I have incorporated from these various contributors to form my philosophical ground for the research.

Following on from this chapter, my methodology chapter will lay all its building blocks on this philosophical foundation, which will then be followed by a chapter dedicated to describing the methods. Its design has grown directly from its methodology with elements from human science orientated research grafted into its data collection and analysis, and blended in with the same underlying methodological signification as the whole project.

## My Journey to Phenomenology

Having grasped the reason for the need to explore my beliefs and values only sometime into the first task set for me by my research supervisor, I then began to appreciate the enormity of the challenge and the necessity of such reflection before considering the philosophical foundations and methodology for this research. I also wondered how it was that I had arrived at my 54<sup>th</sup> year and had never been asked to be so specific in so relatively few words about myself: who I was, and what I believed, how I saw the world and how I searched for and accepted truths about this world. Such ontological and epistemological questions needed to be answered before I could begin to formulate my research questions and decide upon a personally congruent methodology. Once I had located myself within the hermeneutic phenomenological tradition it became necessary to bring my beliefs and values into clear focus within the thesis, and to then work reflexively with these throughout as a requirement of this methodology.

## My Journey through Philosophy

Because I found this subject so new and so complex, I chose to begin my philosophical journey by going back to philosophy's very beginnings in ancient myths, stories created to give meaning to the natural world, and continued this journey through to contemporary philosophers who are similarly seeking to apply their work in the world. This was a mighty trek through history where I found new philosophical ideas constantly being developed with neo versions of previous ideas finding their place alongside these. I delved into each philosophical era constantly amazed at the vast array of philosophical inquiry before me. I found myself identifying with the early philosophers who began to question accepted myths and with the natural philosophers intrigued with their world. I am sure I would have joined Socrates in his questioning, as I find myself questioning everything around me nearly all the time, from my real desire to learn and understand. My questioning however is usually preceded by 'I wonder...' and Socrates, no doubt, would have begun with 'What...?' Although I found myself continually

excited and swept along by each new philosophy, I was less convinced by rationalist ideas and certainly less too by dualist ideas, which seemed to be so prevalent and unquestioned.

I found the Empiricist's ideas of interest, but it was with Immanuel Kant (1724-1804) that I began to feel more at home in philosophy as his ideas seemed to thread together many others and at the same time set the trend in philosophy towards a focus on experience, away from thought and reason and objective, measured observation prevalent in philosophy since Descartes (1596-1650) (Schuster, 2013 p. 196). The existentialist philosophers followed, and although diverse, I found I could identify with their shared focus on ideas emphasising life as it is lived as the source of understanding.

Phenomenologists are found within this group and it was with them that I felt confident in finding philosophers with whom my ontological position would resonate, who would offer clarity for my epistemological framework and a firm foundation for my research questions. I certainly found that the more holistic, non-dualist, relational and rich, lived world approach that characterized their inquiries was enlightening, providing a substantial alternative to the western scientific method which reduced the body to an object, with observation from a distance, that I was beginning to know I needed. Finlay describes this move in philosophy from its limited, confined 'out there' scientific inquiry towards phenomenology in these words.

'Western science has taught us to split mind-body, split mental processes from the physical world. Phenomenology wants us to relinquish our conditioning and to bring together the polarities of mind-body, self-other, individual-social, feelings-thoughts, body-soul, nature-nurture, mental-physical, subject-object. The hyphen signifies intertwining rather than separation; the world does not exist 'out there' separate from our perceptions, rather it is part of us and us of it'. (Finlay, 2011 p. 21)



My training and work as a counsellor is reflective, tentative, relational, mindful and embodied and is concerned to find how life is for the other person, bringing together mind and body, feelings and thoughts and the individual and their worlds. As far as it is ever possible to do so, I allow myself to be immersed in the other's world with them. Then, rather than pointing out meaning, I aim to help let something show itself, a pointing to something rather than a pointing out of meaning (Gadamer, 1986 p. 68; van Manen, 1990 p. 26). Because I could see that this was so near the heart of phenomenological inquiry I readily wanted to read on and find out more about this area of philosophy.

### Husserl: The Root of Phenomenology

Although it is possible to find evidence of phenomenology in the ideas of the Greek philosopher Aristotle (384-322 BC) (Vanier, 2001; Polkinghorne, 2004 pp. 104-127) the Austrian-German philosopher Edmund Husserl is credited with being the founder of modern phenomenology, (Stokes, 2010 p. 148; Macann, 1993 p. 1) this developing primarily as a reaction to the dominant psychologistic theories and positivism. He was cautious of the objectifying tendencies of the natural sciences (Polkinghorne, 1983 p. 224) and losing the 'norms and values that make us human' (Schuster, 2013 p. 196). He introduced the idea of the 'lifeworld' with his focus on the study of phenomena as they present themselves to our consciousness. With his philosophy it was possible to ask questions about people's subjective experience of the world, which then became the central concern of phenomenology and was no longer something that could be passed over in silence (Sartre 1943/1969). Moving from the idea of bodies as mere physiology, Husserl aimed to uncover the full richness of the world and of how things show themselves to us. To do this he believed it was necessary to free oneself from received learning, rather like Descartes before him, and from cultural, educational and religious pre-understandings of our worlds. This process he termed reduction, also known as bracketing, (a subject to which I return in Chapters 5 and 6) giving a lesser priority to this in his later

work. Instead he developed a more natural, embodied response to the world, which other scholars and researchers have since adopted. Again, from my counselling training I was familiar with the idea of bracketing, and while I find this theoretically acceptable to an extent, I find it to be practically impossible. I cannot bracket off myself, my knowledge of phenomena, my life experiences, my history, faith, education and culture before entering the counselling relationship, because this is, I believe, all part of my me-ness and that to have a relationship at all, this needs to be with an empathic, embodied, authentic human being. Of course I readily attempt to put aside judgements and stereotyping and want to approach my clients in an open way and similarly in my research, seeing, hearing, feeling and touching my clients' and research participants' worlds and lives in all their uniqueness and fullness. So, because of Husserl's focus on phenomenology as a science to study the essence of conscious experience and because his work was not tentative, reflective or interpretive, I knew this precise epistemological framework was not appropriate for my research, but encouraged I continued looking amongst other phenomenologists.

### Developments in Phenomenology

This search was far from fruitless. I found that other philosophers had since developed Husserl's original phenomenological project and it was amongst these that I found ideas that were most congruent with my own and which have shaped this research project. Of these, no one philosopher dominated, so I engaged with the ideas of several, not merging these to make a new philosophy, but rather bought them together to make their own discrete contributions to my research. My attention was particularly taken and my interest inspired by a clear move away from Cartesian ideas towards non-dualist ideas of embodied being in the world, of the importance of relationships, and of existentialism, considering the importance of the individual experience of existence, and it was Heidegger's use of poetry that first encouraged me to consider the rich hermeneutic possibilities of including this creative art-form.

Heidegger, a student of Husserl called for an existential correction of Husserl, being less interested in the study of consciousness and more interested in the study of the meaning of the verb 'to be' or 'being' (Heidegger, 1927/1962). He also moved away from his dualistic ideas of people as separate from the world but instead saw self and the world as a single entity. While these corrections encouraged me further, I found his ideas to be essentially gloomy with his belief that people would stop questioning and therefore stop learning, and hopeless with his ideas of angst because of his belief that there was nothing after death. Instead I believe human nature is fundamentally questioning and wondering, which are aspects central to this research, and purposeful for the most part. Heidegger also believed people would become 'beings of others' (Ibid.) a concept I also found difficult because of my belief that humans are essentially relational, another idea central to my research. So, while I could not accept much of Heidegger's philosophy, it certainly seemed to have fuelled further philosophical inquiry in me.

Gadamer extended Heidegger's main concepts, also believing that Husserl was misdirected to consider that the search for knowledge could be unconditioned by culture and history. Instead he believed these would colour how we understand our worlds, that we 'cannot escape the historically conditioned character of our own understanding', that we cannot approach objects as 'value free' as with objective science (Polkinghorne, 1983 p. 225; Gadamer, 1975/2013) and he considered 'perfect enlightenment illusory' (Gadamer, 1975/2013 p. 580). Gadamer also introduced the idea of the 'fusion of horizons', a dialectical interaction between the meaning of a text and the understandings of the interpreter, leading not so much to a truth, but a constructed interpretation. This has been important for my research as I believed it honoured both the original text and the interpreter's involvement. Gadamer also developed Dilthey's (1833-1911) ideas of the hermeneutic circle (Dilthey, 1900) as another method for understanding texts, a movement from parts of it to the whole and back again, to increase the depth

of understanding. I have also incorporated this process in my textual analysis and found to be helpful. And finally, Polkinghorne's summary of Gadamer's philosophy that,

‘we want to know what is useful, how to act in this situation, and how what we are learning fits into what we have already understood.’  
(Polkinghorne, 1983 p. 225)

together with Gadamer's cautions not to be ‘tempted to extrapolate’ data ‘beyond their limits’ (Gadamer, 1975/2013 p. 578) have together remained most important to me from his ideas and continued to pave the way for my research.

By this stage in my journey I was certain that I did not want a philosophy that championed precision in its analysis and could not include the ambiguous and denied the value of interpretation. I knew that I could not risk losing the character and individuality of the experienced world so wanted a descriptive, hermeneutic system that valued a person's lived experience. I wanted to meet with others, to hear, see and feel them communicate the unique meanings they found in their person-centred care of people with dementia, and this from my being in the world of my research participants. I knew this philosophy was the ‘lantern’ to which Nietzsche was referring when he said ‘Whoever is searching for the human being first must find the lantern’.  
(Buytendijk, 1947 p. 22 in van Manen, 1990 p. 4)

In my counselling work, I encourage people to share with me how life is for them and by this I aim to immerse myself, as far as I am able, into their worlds, to feel a deep empathic knowing through their words and our embodied being together. I do not aim to diagnose or prescribe, so much as to voice back what I am hearing or feeling, which in turn helps the person to hear, maybe in clearer tones, perhaps even for the first time, what they themselves are saying, feeling or experiencing. These further parallels with existential hermeneutic phenomenology were, by this stage so familiar and clear, it seemed even more reassuring.

It was however, when I began to read the work of Maurice Merleau-Ponty the French existential philosopher, and Martin Buber, the Austrian born Jewish theologian and existential phenomenological philosopher, that I found I really knew I was meeting with ideas in near perfect harmony with my own emergent ontology and epistemology, and knew these two would be the main-stayers for my journey, as rhythm to set the pace with melody and words to inspire. They were the fuel for Nietzsche's lantern, the walking boots and the music while I walked. Although very different in their focuses, I found their existential hermeneutic phenomenology to be congruently tuned together and so, with some further input from Heidegger, Gadamer, Lévinas, Gendlin and Vanier, I had arrived, ready set for this part of the journey with all I needed.

### Maurice Merleau-Ponty

Merleau-Ponty was 'steeped in both Husserl and Heidegger' (Todres, 2007 p. 1) and to some extent Sartre (1905-1980) and de Beauvoir (1908-1986) who were his contemporaries. At the centre of his dialectical philosophy was what seemed to be a constant emphasis on the foundational role of perception for understanding the world, seeming to be in tune with some of Kant's ideas. However, Merleau-Ponty's development of the definition of perception beyond Kant's seemed more holistic and dynamic to me with the intermingling of all sensory possibilities being the means by which objects appear and are known. He described this, writing,

'We have the experience of the world, not understood as a series of relations which wholly determine each event, but as an open totality the synthesis of which is inexhaustible'. (Merleau-Ponty, 1945/1962 p. 219)

By engaging in the world in a bodily way, consciousness is practical, perceptual and embodied and much more than the sum of the data received by our senses and processed by cognition (ideas developed by Gendlin, 1973, 1978/2003, 1992, 1997, and now incorporated into my research

methods). Merleau-Ponty believed that there would be an infinite number of possible outcomes from this, which seemed to explain so well the wide variety of interpretation, opinion and understanding that can arise from a single event. Since beginning this research, I have realised that philosophy and philosophers are not excluded from this, with their different ideas about how we acquire knowledge and of what knowledge is important. There also seemed to be, from my observation before this research ever begun, diversity in the experience of care giving amongst nurses caring for people with dementia and in their interpretations and application of care while using standardised practices. For people with dementia such differences seem evident to me too. For instance, during a recent visit to a care home, one resident seemed happy with her life and full of praise for her care, while another in the next room shared her longing to leave and find another home in which she might feel more 'at home'. As a professional working in such contexts, different homes engender different feelings in me too. In such situations it is impossible for me to ignore this, but, as I listen to others, I attempt to hold my own experiences at bay to be more attuned to others' living experiences. All three of us experienced the same care home but each of us recounted a different life story and response concerning this. This reflection is helpful because these ideas have been central to my research. While knowledge about the phenomenon of person-centred care has been derived from individual's accounts of their experience of this, it has been impossible for me to ignore my own experience of the phenomenon. Instead I have welcomed and acknowledged this as a necessary and positive influence on the whole project from its conception to the last page of text. My experience has been an open gateway for this research and also its sustenance. My experience has given me eyes to see, ears to hear and a heart to feel into others' lived experiences (van Manen, 1990 p. 19 & 40).

Merleau-Ponty's ideas of the body as the 'vehicle of being in the world' (Merleau-Ponty, 1945/1962 p. 82) which he later described as 'flesh of the world' (1964/1968 p. 146) through which we are connected to the world and

through which we can understand the world, seemed so very logical to me. I found his further ideas of the subjective body and objective body to be equally interesting as this seemed to answer some of the questions I found myself asking about others' experiences of others' bodies, which sometimes seem to be an objective body. It may also, in some way, explain the feelings of sadness and loss I experience when I hear relatives and staff making objective statements about a person, who to them, through the process of illness, may have become 'a contained, material, biological thing' (Finlay, 2011 p. 55) and less recognisable as the person they knew. Merleau-Ponty talks of the 'wholeness' of the 'cripple' (Merleau-Ponty, 1945/1962 p. 82) and this to me emphasised his belief that a person *is* their body, and cannot be reduced to matter or physiology, no matter, as in Merleau-Ponty's discussion, about amputated limbs or damage to the flesh. The person *is*.

Merleau-Ponty was therefore very much a non-dualist who believed that 'the mind is not a thing distinct or separate from the body' (Carman, 2008 p. 97) and that 'the body is just the self' (Ibid. p. 131). Merleau-Ponty did not see the mind lurking behind a body, but rather as incarnate within. He also believed that the embodied person and the world were intertwined in such a way to make them inseparable and Carman summarised Merleau-Ponty's ideas of 'flesh-of-the-world' by 'we are not just *in* the world, but *of* it' (Carman, 2008 p. 133). The substance of this flesh of the world, this intertwined body, was never described as matter by Merleau-Ponty but instead he used the more complex expression 'the coiling over of the visible upon the seeing body, of the tangible upon the touching body' (Merleau-Ponty, 1964/1968 p.146) to describe it as an integral, essential and inseparable part of the whole.

This idea of 'flesh of the world' was a development Heidegger's idea of being-in-the-world, which Finlay describes as philosophy being brought 'down to earth' to 'capture our embodied way of being' with world and body being 'within one another and intertwined/criss-crossed' (Finlay, 2011 p. 56).

This powerfully poetic imagery caused me to reflect upon a beautiful sculpture on a doorway in Chartres Cathedral of which I first became aware while reading Vanier's book *The Broken Body* (Vanier, 1988 p. 17) and then studied in more detail in *The Creation of Adam* (Runcorn, 2001). In this, God is in the process of creating Adam from the earth itself. He is quite clearly reaching 'down to earth'. Because this is such a powerful metaphor, holding so much of what is important to me, I have made further reference to this in Chapter 2 and Appendix A.

Murray (2012), while not using all of Merleau-Ponty's language, nor the sculptor's skill in stone, appeals, together with Husserl (1936/1970 p. 270) for their joint wisdom in medical care. He believes that care, structured by bioethics, formed by reason and with beliefs in autonomy, has resulted in bodies being seen as mere physiology and life as biophysiology. Like Merleau-Ponty he calls for ideas of the speaking lived body to inform medical care which he believes has lingered too long with the mental activity of the patient separated from their body. He is therefore concerned that human bodies may be considered only as spare parts to be exchanged or modified. Because I believe it is essential to be confident in our models of care and of the origins of the ideas behind them, Murray's concerns, reflecting and contemporizing so many of Husserl's and Merleau-Ponty's ideas and calling for phenomenology to be considered as a new epistemology to inform practice, were important to me. Interestingly Buber gives similar attention to the quasi-biological, seeing it as a 'sickness of our age', which is getting worse (Buber, 1937/1953 pp. 55-56) and Galvin and Todres more recently have said they believe 'something is missing in our health and social care' (Galvin and Todres, 2013 p. 1) and express a need for more humanised care with a 'lifeworld approach' (Ibid. p. 5).

Merleau-Ponty's account of our bodily co-existence with others, begins with him asking questions about personhood, which are answered by his belief that we are not just owners or subjects of experience, but bodily beings and



encounter others with whom we share a common material world. Carman (2008 p. 135) suggests these ideas to be one of the most original and important elements of his phenomenology and certainly will be for me as a researcher. Merleau-Ponty describes the world as a world in which one is not cut off from others, even though a person's experience of the world is unique, but is one of relationships with others, in and through our bodies. He says that we perceive others as human bodies like ourselves, and not as material objects, because others are already known as persons like ourselves. However he also says the 'other's gaze' may lead to objectification and the denial of personhood when actions are not understood and people observed 'as if they were an insect's.' He qualifies this by saying that,

'This is what happens for instance, when I fall under the gaze of a stranger. But even then, the objectification of each by the other's gaze is felt as unbearable only because it takes the place of possible communication.' (Merleau-Ponty, 1945/1962 pp. 360-361)

These words jumped off the page to me as I read them because they offered some more insight to me as to why some people with dementia may feel dehumanized in care homes and hospitals. The gaze of others, the carers' or nurses', may actually be for medical observations, or to make an assessment of a person's holistic care needs. Their intention could be misinterpreted and therefore misunderstood as 'observation', possibly making that person feel dehumanized.

To summarise this discussion, I found Merleau-Ponty's ideas were formative and powerfully enlightening, meeting much of the foundational criteria I needed for this research, with the key principles I have adopted being,

1. Embodiment, the non-dualist, pure synthesis of body, mind and spirit of a person to intuit meanings.
2. Flesh of the world, the intertwining of body and the world, emphasising relationships based on the shared humanity of researcher and participant.

Merleau-Ponty's philosophy was not only foundational for me as a researcher and for the development of my project but had also become a platform from which to explore other phenomenologists' ideas. This was particularly so for the interest he had sparked in me concerning relationality, which lead me towards Martin Buber's philosophy.

### Martin Buber

I had briefly encountered Buber's work during my counselling training and although I did not read his work in much depth at that time it left a lasting impression on me. I could see his significant influence on the work of Carl Rogers (1902-1987) (Buber, 1966; Rogers, 1951, 1967/2004, 1980) the founder of Person-Centred counselling theory and practice, which formed much of my training.

Buber was an Austrian born, Jewish theologian, educator, existential phenomenological philosopher, and prolific writer but best known for his work *Ich und Du*, usually translated as *I and Thou* (Buber, 1937/1953). He was introduced to philosophy at an early age through his study of Plato and soon after read Kant's *Prolegomena* which he described as 'delivering and helping' for addressing the philosophical questions of time with which he was struggling, and which he also said 'exercised a great quieting effect on me' (Buber, 1973 p. 27). However, it seems that neither of these philosophers, nor any others, had much influence on Buber's thesis, which appears to have been quite unique in its time with its questioning, almost poetic style proposing the premise of existence as encounter. Because of the more spiritual dimensions of human relationships about which he writes and of these linked to the relationship between God and man, I was even more drawn in by his writings as his ideas fitted well with my own beliefs. This was encouraging for me, but knowing of Buber's considerable influence in the secular world was more encouraging. Rogers, who had rejected his earlier Christian upbringing, drew heavily on Buber's ideas, his Person-Centred theory remaining predominant in humanistic counselling throughout the world

(Merry, 2002, pp. 1-4; Merry and Tudor, 2006 p. 293). Martin Luther King Jr. also drew much from Buber's thesis and often quoted him, particularly in his letters from Birmingham jail in 1963, and on the subjects of exploitation, racism and discrimination, subjects very much of the world (Baldwin, 1991; Walton, 1971 pp. 44-45). These examples give some evidence of Buber's contributions to others' thinking, outside of the religious perspective and of the application that is possible in secular contexts. With Buber's own vision for finding God being 'all about how you live in the world, and not at all about finding and serving a big invisible man in the sky' (Margolin and Pessin, 2008 p. 2) I was encouraged to believe his work would be of significance to my research and would not be limited by Buber's religious persuasion. Vanier's further development of Buber's ideas was equally encouraging to me as in his ethical philosophy he fleshes out in practice, much of Buber's philosophy (Vanier, 1992 p. 49; 1999 pp. 81, 133; Vanier and Swinton, 2014, pp. 87-88).

In *I and Thou*, Buber explains his philosophy using the two word pairs Ich-Du translated as *I-Thou* and Ich-Es, *I-It* (Buber's italics) to categorize the modes of consciousness, interaction and being through which an individual engages with other people and with all innate objects. He writes 'These do not signify things but they intimate relations' (Buber, 1937/1953 p. 3). They express complex ideas for relating, which Buber argues will always be by one of these modes, continuing his thesis by describing each of these 'primary words' in considerable detail. Interestingly his thesis, like Merleau-Ponty's, includes clear references to the body, but Buber's focus is more on communicating with the other with the body, whereas Merleau-Ponty's emphasis is on the embodied self. Buber says 'The world and I are mutually included, the one in the other' (Buber, 1937/1953 p. 93) and interestingly too, Vanier's focus is also 'founded on the body' like Merleau-Ponty's embodied being, and develops Buber's focus on the embodied self as the means of communicating with another (Vanier, 2008 p. 109).

Buber describes *I-Thou* as a relationship, which stresses the mutual, holistic existence of two beings in a concrete encounter, meeting each other in their authentic existence without any qualification or objectification of one another, with no need for structure or content and with *I-Thou* only being possible with the whole body (Buber, 1937/1953 p. 11). He uses a variety of examples to illustrate *I-Thou* relationships, which include two lovers, an author as he contemplates a tree, and an observer and a cat. Although I believe the word 'Thou' in English carries a meaning quite different to 'you' I nevertheless find it difficult to provide an alternative word for this, but can understand something of its intended meaning by how it makes me feel. Attempts have been made to describe it as encounter, meeting, dialogue, and mutuality, but I believe none of these words can hold, in themselves, all of Buber's meaning. Interestingly, Buber acknowledges that *I-Thou* cannot be proven to happen as an event, nor be measured, but stresses that it is real and observable (Buber, 1937/1953 p. 109). This is very interesting because it emphasises Buber's experience, or observation of *I-Thou*, to know of its existence, relying neither on reason nor measurement, fitting very well into a phenomenological epistemology. As I have listened to the experiences of people caring for people with dementia throughout this research, and have immersed myself in the texts describing these experiences and then reflectively 'listened' again, I have, as the researcher, gained new insights and know more about these experiences.

Buber further qualified *I-Thou* as a meeting which could not be found by actively seeking for it, but which is only possible by grace, with movement towards another enabling the other's free movement towards me. He described such meetings as 'real living' (Buber, 1937/1953 p. 11) that give rise to relationships which are free from judgement, narcissism, demand, possessiveness, objectification, greed or anticipation, ideas also taken up by Vanier in his book *Encountering 'the Other'* (Vanier, 2005). I know, from my own experience, that when I feel most 'alive', experiencing Buber's 'real living', is when I am in such a relationship with another person, or as I absorb

some of the beautiful scenery around me. I know this *I-Thou* to be true as I sense I do 'move towards' beautiful coastal landscapes and almost 'embrace' them as I am filled with their wonderment and powerful peacefulness and with something like exhilaration in which I know I am truly alive.

Although Buber said that *I-Thou* relationships could not be found by actively seeking them, as this objectified the relationship as a 'need' or 'desire', he said these would come if there was no attempt to reach out and grasp at *I-Thou*. If they are summoned or tightly held onto they would vanish, as this would reinstate control. Similarly he also believed that it was impossible to make another touch your soul, but said we must let a person, or object, touch the depth of our being. He qualified this by saying that it would not always be easy as this could make the world seem like a dangerous, uncontrolled place (Buber, 1937/1953 pp. 33-34).

Buber also wrote that *I-Thou* relationships were a means for personal growth as such relationships were mutually revealing, recognising the value of the other's personhood. He wrote 'through the *Thou* a man becomes *I*' (Buber, 1937/1953 p. 28). This idea has also been developed by Vanier and very clearly applied in the communities of L'Arche in which he has had a foundational and on-going role for fifty years. In these communities, people with various disabilities and others, come together to live and work, and in this coming together, of movement towards the other, it is Vanier's belief that those without disabilities (known as assistants) and people with disabilities (known as welcomed people) both grow. Then, through the communities' work and involvement in the wider communities in which they are situated, further movements towards others are facilitated. These communities are deeply relational, places of *I-Thou* and places where people come to know and grow in their selfhood, their '*I*' (Vanier, 1988, 1992, 1998, 1999, 2001, 2008, 2008, 2013, 2014; Hauerwas and Vanier, 2008). I have been privileged to have discussed this research with Jean Vanier and have visited three L'Arche communities and in each I saw deeply moving and beautiful *I-Thou*

relationships where there were so obviously no attempts to control the impressions being created, where people were so clearly at home, where people were comforters and were being comforted, and were freeing and so clearly free. I can provide no evidence for these, as Buber suggested I would be unable to do, apart from what I know to be true from this experience. Such meetings with others have been important throughout this research.

Buber did not write as negatively as one might expect about the nature of *I-It*, but said such relationships were equally important although never 'spoken with' the whole body as *I-Thou*. He also described a more usual oscillation between the two, where relationships change from *I-It* to *I-Thou* and from *I-Thou* to *I-It* quite seamlessly. These relationships are very different in that in *I-It* the beings do not actually 'meet'. Instead the *I* qualifies an idea about, or conceptualises the being in its presence and treats that being as an object, created and sustained in the mind, reminiscent of Kant's (1781/1999 p. 113) ideas of objects existing only in the thoughts of the cognitive agent's mind. Buber described this as more of a monologue or a relationship with oneself, and not of dialogue, where the other remained a stranger and where things could be controlled and organised and thus be very safe (Buber, 1937/1953 p. 31-32). When I first read this, it caused me to wonder if, in our best attempts to provide excellent care for others, with structured care plans, models for care and strategically designed systems, we can perhaps lose the person through this and be left only with a stranger to be cared for by a stranger. I have developed this reflection in the light of the research findings in Chapter 8, together with Galvin and Todres' (2009a p. 145; 2013 p. 12) ideas of open-heartedness and open-mindedness. Further qualifying the need for *I-It* Buber wrote 'Without *It* man cannot live. But he who lives with *It* alone is not a man' (Buber, 1937 p. 34). McCormack and McCance (2010 p. 24-25) and Vanier (1999 p. 133) have also taken up these ideas, both saying that part of being human is expressed in our caring for others, which I have also returned to in more detail in Chapter 8. Because of the possibilities of missing the essentials of being human and of the potential for objectification

of another, Buber cautioned against a world of *I-It* as he believed this would lead to binding up, suppression, observation instead of 'gazing', and instead of acceptance, change would be sought for personal gain, leading to further hardness, coldness, isolation and to dehumanization. Of institutions with only *I-It* relations Buber said these would be places in which one 'neither knows the person, or mutual life' (Buber, 1937/1953 p. 44).

In the second and third parts of *I and Thou*, Buber gave more attention to ideas about God, whom he called the 'Eternal Thou', 'The Being of Beings' and 'The Face' and of God's relationship with people and peoples' relationship with him. Of fundamental importance to Buber was his belief that nothing in the world could separate man from God (Buber, 1937/1953 p. 95) and that through an *I-Thou* relationship with God, a person was free to be able to listen to and relate to and give generously to the other. Vanier was influenced by Buber's ideas when he described community as a place of meeting. He wrote,

'Martin Buber said that community is a place of theophany. It is a place where we meet God in very intimate relationships.'  
(Vanier, 1992 p. 49)

This meeting with God in others, where 'God surrounds us and dwells in us' (Buber, 1937/1953 p. 104) which Buber said was not just 'subconsciousness or any other apparatus of the soul' (Buber, 1937/1953 p. 109) but a known reality, resonates with my belief in the transcendent nature of relationships and was real for me in my relationships with the participants. It was therefore important to me to ensure that my relationships were caring, dignified, respectful and honouring *I-Thou* relationships, in which the participants would never become objects in my research. I believe this idea is expressed so beautifully in the closing scenes of the film *Les Misérables* (2013) with the words 'To love another person is to see the face of God'.

Buber's attention in his thesis to the discussion of the nature of *I-Thou* and the 'Eternal Thou' confirms him as a true phenomenologist as he describes a

person's journey towards another. Buber made it clear that a person would only know his or her part of 'the way' but could come to learn more as he moved towards an other, 'as it comes upon him in the meeting' (Buber, 1937/1953 p. 76). I love this imagery and know that this will be part of my epistemological framework as I move toward the other and welcome them and their experiences, which I then hope will give me a new, fuller and deeper knowledge of their experiences of person-centred caring. Buber's work is packed with ideas and images and poetry and to me was enormously inspirational and resonant in just about every part of me and therefore has been directional in this research. I know from my own lived experience, that relationships are essential to our being in the world and should I be required to use Buber's 'infallible test' (Buber, 1973 p. 61) I would certainly choose other people rather than books, if I was alone in the world and given the choice!

So, in summary, the principles I have adopted from Buber's philosophy to frame my research are,

1. The importance of *I-Thou* relationships as the means of being in the world of the research participants.
2. Learning more about others' lived experiences from *I-Thou* relationships, not by 'grasping' at what might be 'real' but by moving towards others and letting their lived experiences 'touch me' in the 'depth of my being'.

### Blending Ideas for this Research

By taking what I have needed, principally from Merleau-Ponty and Buber, but also from Lévinas and Gendlin, I was able to create a final framework representative of my ontological position and epistemology for the grounding of my research. In this blending I did not dilute either of these philosophers' distinctive theses, nor lose anything of their specific intentions. Each element has remained recoverable and recognisable yet supplemented with other philosophers' ideas. I knew that my wondering curiosity and passion to



discover more about nurses' experiences of person-centred dementia care could grow in this philosophical ground but I also appreciated that my ability to remain open to new understandings, going beyond what I knew from my experience and limited established knowledge not being a nurse, would be challenged. My intention was therefore to attempt to 'be fully and continuously engaged in managing intrusions of pre-understandings throughout the research' (Finlay, 2012 p. 176) and hoped to make inquiry a 'continuous beginning' (Merleau-Ponty, 1964b p. 161). My research does not therefore have a rigorous scientific approach to the 'reduction' (Merleau-Ponty, 1945/1962 p. xiv) but my researcher influence has been acknowledged and worked with reflexively throughout. Embracing Merleau-Ponty's ideas of, 'I am my body' (Ibid.) I could not but bring this and all that is *me* to this research. The passion for this was stirred up *in* me and will be accomplished *in* me. Buber's ideas of the journey towards the other with wondering curiosity has also been important, in its empathic nature, slower pace and gentler way to revelation of the other as 'it will come upon me in the meeting' (Buber, 1937/1953 p. 76).

While Merleau-Ponty's work includes ideas concerning meeting others in the body and the importance and nature of the meeting, Buber's thesis is fuller and richer in its descriptions. They both discuss ideas of objectification in such encounters, with Merleau-Ponty saying that the other's gaze transforms a person into an object and thus denies *them* (Merleau-Ponty, 1945/1962 p. 167). This becomes unbearable because it takes the place of possible communication. Buber says that such objectification by human consciousness, has set up a barrier and separation so that others become strangers and cannot be known nor therefore can anything of the other's lifeworld or living experiences (Buber, 1937/1953 p. 23 and p. 32). He says that in times of sickness, when the 'inflowing world of *Thou*' like 'living streams' is absent, the world becomes a world of objects with no sense of 'present being' and is like a 'stagnant, gigantic ghost' (Buber, 1937/1953 p. 54). These were strong images, which I knew to be true, to some extent,

from my own experience of caring for people with dementia. However, I sought to hold these at bay while I immersed myself in others' experiences allowing their rich descriptions to lead to new understanding. I knew that if I were to employ a rigorous scientific method to 'observe' nurses and analyse them, I could objectify them and thus risk losing them and any hope of answering my initial question. Instead, by my embodied meeting with nurses in a way more akin to a companion on a journey, of walking alongside the other, I hoped I would be open to what could emerge from the other and from myself in response, to reveal new and subtle depths of meaning (Buber, 1937/1953 p. 59).

Buber's and Merleau-Ponty's ideas of the embodied person have also been important in this research, not least because this word is within the model of care, the experience of which I have investigated. Merleau-Ponty is emphatic in his assertions that a person is not simply the owner of subjective experiences, but a bodily being, who perceives others as human bodies, not as material objects or separated beings of mind and body. Buber affirms these non-dualist ideas (Buber, 1937/1953; 1957/1974 p. 211) and Dufresne (2009) makes Vanier's position clear. I had no trouble embracing these ideas, even though they are incompatible with much, though not all, Christian thinking from Aristotle to the present, in which a person is more usually understood as body mind and spirit in separate parts. I found that these non-dualist ideas had become liberating. Merleau-Ponty's idea concerning the transcendent nature of others was also important for my research. While I understood myself to be my body, as now, sitting at my desk, at a place and time in history and a very finite contained person, the 'other' could only be described as transcendent. They could never be fully known and could not be possessed by me in my mind (Merleau-Ponty, 1962 p. 369). This was important to recognise because using these ideas for my epistemology meant I was not able to produce any statement of fact, any posteriori knowledge concerning another person and their experiences, but instead would lead the reader to a questioning wonder and to new insights.

Lévinas had similar ideas, expressed as the alterity and infinity of the Other in an asymmetric relationship which was always elusive (Lévinas, 1961/1969 p. 80) and Vanier frequently makes reference to the other, with L'Arche being a place where "On est tous pareils, on est différents" (everyone is equal, everyone is different). Buber mirrored these ideas with his starting point of 'ne connaissons-nous jamais l'homme?' (Will we ever know the man?) (Rousseau, in Buber, 1947 p. 140) in his discussions of personhood, and answered it saying that it was never possible to know a man, but that we could come nearer the answer to the question of what man is, when we come to see him 'as the eternal meeting of the One with the Other' (Buber, 1947/2002 p. 244) and 'in community' never distinct and separate from others (Ibid. p. 175). In summary Buber said 'The *I* is impossible without the *Thou*' (Buber, 1947 p. 250). These ideas have been central to my work as the researcher, needing to honour the research participant not only as 'Thou' but also, as *I-Thou*, for them and their lived experiences to become accessible and in any way known to me. This left me wondering what others' beliefs about the nature of personhood might be and if this might influence a carer's application of person-centred dementia care. As a developing phenomenologist I was reminded that further reflection on this needed to wait, and that I needed to allow the participants to speak of their own experiences and for me to listen as unencumbered as possible by my own developing ideas. I needed to let the data reveal what it would.

It seemed that a natural development of this for Buber was attention to the varying effects *I-It* and *I-Thou* can have on the shape of communities. These ideas were especially important to me as so much of my work takes me into structured and often closed communities, because my research participants work in these, and because of what I had experienced in L'Arche communities. Both Buber and Vanier say that by entering into relations, a man can be 'confident in his soul', 'build a special conception of space, dwellings for God and man' and will 'fill swaying time with new hymns and

songs, and shape the very community of men' (Buber, 1937/1953 p. 54). This was Buber's beautifully poetic, rich language which seemed to provide something of a key to what may be needed to develop communities in which people are more confident, happier, more animated in their bodies and have a special 'relationship' with the space in which they live, maybe even towards an idea of it being 'home'. Again I had to hold such imagery and ideas at bay, to allow the research data and my reflection upon it to speak for itself. This was helpful direction for my methodology and for how I would engage with the research participants. I wanted them to be confident in their souls and for us to be able to really meet as *I-Thou*.

Finally I must address the subject of spirituality because my faith must express itself in my work for this to be authentically of me. While Merleau-Ponty's work includes references to spirituality, Buber, Lévinas and Vanier emphasise a spiritual dimension to human relationships between God and man, believing God is glimpsed through encounters with others. These ideas appealed to me, not only because this is very much part of my own experience, but also because this leaves no one without the potential for a relationship with God. They all allude to a transcendent God becoming visible and known as we reach out and move towards another person and Buber says 'He who truly goes out to meet the world goes out also to God' (Buber, 1937/1953 p. 95). I have referred to this idea of reaching towards others later in this research, knowing that this movement towards the other will have been part of the means of discovering people's experiences of person-centred dementia care. The song I referred to earlier from *Les Misérables*, which includes this active verb to love, reiterates, almost exactly, Buber's words and because I have had that song in my mind for so long, I know I took Buber's words, quite literally, with me into this research.

## In Summary

In summary therefore, the core philosophical principles I carried with me into the research to enable me to access descriptions, essences and meanings of person-centred dementia care, as in Diagram 1 are,

1. The central role of relationships for being in the world.
2. Coming nearer lived experiences through movement towards the other in *I-Thou* relationships.
3. The non-dualist synthesis of the body, mind and spirit in such relationships.
4. Flesh-of-the world, the intertwining of body and world emphasising the capacity of the body to speak beyond words.
5. The existential valuing each person's personhood, uniqueness and unique experience of the world.
6. Hermeneutics for drawing the participants and my interpretations of lived experiences together.

Diagram 1: A Diagrammatic Summary of the Philosophy



## The Next Part of the Journey

I spend all my working days with people with dementia and with people who care for them. I care. My passion has fuelled this thesis to discover nurses' experiences of person-centred dementia care. So, having taken on board Merleau-Ponty's call for true philosophy to learn to re-look at the world (Merleau-Ponty, 1962 p. xx) I needed to begin my journey towards others' lived experiences with a methodology formed from this philosophy. This would offer me the epistemological pathway to its destination. Although, at this stage I did not know the precise destination for this journey, just its orientation (Merleau-Ponty, 1962 p. xxi) I considered myself well prepared, with a pair of very robust, well-worn walking boots on my feet, with lashings of essential supplies and with the expectation of some good company along the way (or, in other words, a blended epistemological framework grounded in some of the philosophical tenets of Merleau-Ponty and Buber and other phenomenologists, forming it as a distinctly existential, hermeneutic project). So it was with increasing enthusiasm and considerable confidence that I continued into this research, feeling almost perfectly reconciled to this philosophical tradition, quite at home within it, and certain that an existential hermeneutic phenomenological methodology was an ideal framework. I trusted the process and all that it had in store, albeit with only a dim horizon visible ahead in its early stages. The following chapter, Chapter 5, is focused on the methodology built upon this philosophical foundation.

# Chapter 5

## The Sketch Map: Methodology





## Chapter Five: Methodology

### The Sketch Map: Introduction

‘He who takes a road that in its nature does not already represent the nature of the goal will miss the goal, no matter how fixedly he holds it in sight. The goal that he reaches will resemble the road he has reached it by.’ (Buber, 1957/1974 p. 105)

This chapter will concentrate upon the methodological principles for the research, the interrelated parts of which I have termed components. They are a development from the philosophical framework, which formed its foundations as described in the preceding chapter. The subsequent chapter concentrates more precisely upon the principles I have used to structure the research within which all the components of the methodology described here find their place. I will begin this chapter though with the following reflection.

I hope that you the reader will know something of that wonderful feeling which can be somewhere near delight or even elation, when you have found something. This could be either finding something out, or finding something that was lost, or it could be a penny-dropping moment when you first understand the real meaning or significance of something, or something is realised for the first time and could maybe even be called a revelation.

I had such a moment a few months into planning this research, which while it was not quite as dramatic as some revelations can be, it certainly was significant. During a supervision session my supervisor, quite out of the blue, or so it seemed, asked me if I was like a filling in a regular sandwich or more like a toastie in which the filling has seeped through in the cooking process. I was rather confused by this for a while, as you can imagine, until I recalled my first ever face-to-face meeting with this same supervisor who then, seemingly unconnected to our conversation, asked me if I liked dance. At the time I wondered if this was some radical assessment test for prospective PhD students and I have to say I was, fleetingly panicked by this. Did she

mean, did I like to dance, or dance the art form and I wondered why she was asking me anyway? The resolution of that situation will have to remain a mystery for now, but I will return to the sandwich. Recalling the conversation about dance was enough time for the metaphorical penny to drop. In my turbulent reflection, a whirl-wind enhanced dance through the last few years, I knew that I had moved from hermeneutic phenomenology being a 'this is it' as the methodology I had used for my MA research dissertation, to 'I am it'. I had come to a point where I felt I could say I was a phenomenologist. The strange workings of metaphor! I am now very confident that, not only is most of my thinking in line with many phenomenological philosophers, and most of my ways of learning and working are broadly phenomenological, but also that hermeneutic phenomenology is the most natural methodology for me in this research. I am sure too that this will underpin any further research I may undertake in the future and that knowing now how close this is to my being, this knowledge will help guide me more confidently towards any new fields of work in the future. I now feel immersed into and inseparable from phenomenology. It has seeped into me, is intertwined there in every aspect of my life and dances through it. Phenomenology is therefore both the philosophical underpinning for this work and existential hermeneutic phenomenology (EHP) its methodological sketch map.

### Other Methodological Considerations

Because of my growing belief that it is 'impossible to reduce the meaning of things to numbers' (Seager, 2014) and that the world is incomprehensible but certainly 'embraceable', (Buber, 1957/1974 p. 27) I had already discounted any quantitative methodologies for this research. I did however, in the early stages of its planning, consider other qualitative methodologies from the 'baffling range of choices' (Finlay and Evans, 2009 p. 13) including, interpretative phenomenological analysis (IPA), heuristic and grounded theory and was interested in more recent developments in relational-centred research (Finlay and Evans, 2009; Finlay, 2011). While elements of these and others will be included in this research, none seemed to take me over

and enthuse me quite like EHP, nor did they seem to be as rich and as powerful for the research I had in mind and the questions I wanted to answer through the process of this research.

Although I initially considered an IPA methodology for my research, I became increasingly aware that the need for analysis to be, 'thorough and systematic' (Smith et al., 2009 p. 29) with 'detailed examination', using 'analytic procedures' (Ibid. p. 32) and 'numeration' (Ibid. p. 98), did not fit well with the project I was considering. I did not envisage myself as an 'analyst' (Ibid. p. 88) of human lived experience identifying and counting recurring themes (Ibid. p. 107) but as more of an artist, wanting to find what was unique in the lived world and to then bring this to attention. Further to this, I became increasingly interested in the flexibility and creative possibilities I was finding within EHP, which I believed could be stifled with IPA.

The need to follow 'explicit guidelines' (Mintz, 2010 p. 3) in grounded theory did seem initially appealing because of the relative safety of using such a framework. Further to this, seeing the participants as co-researchers (Finlay and Evans, 2009 p. 199) added to its attraction. However, with its further aim to 'develop a theory or model of the phenomenon' (McLeod, 2003 p. 88) I felt I would be straying away from my developing interest in creating my own research design and being creative in the expression of my research findings. Further to this, I became increasingly more convinced that EHP could reveal the uniqueness of human lived experience and that its creative potential could continue through the readers' engagement with my writing, rather than ending with a more generalized new theory or model.

Heuristic inquiry, developed by Moustakas and Douglass (1985) did however seem more promising because of its emphasis on using 'self' as a major tool, (Etherington, 2004 p. 16) moving beyond the cognitive processes into connecting with body, mind and spirit' (Ibid. p. 126). My 'self', together with my training and experience are the essential 'tools' for my work as a person-

centred counsellor so I felt comfortable with a concept 'parallel(ing) with good therapy' (Ibid. p. 126). Further, Moustakas also drew on Buber's philosophy, Maslow's research on human growth and flourishing, Rogers' person-centred theories and Gendlin's work on focussing, (Finlay, 2011 p. 163) ideas that were already well known to me and which underpin much of my practice, thus further adding to its initial appeal. However, I became concerned that this methodology risked taking me too far from my aim of describing and interpreting lived experiences, and then searching for the essences and meanings of the phenomenon for my research participants, by potentially focussing too much on my own introspective 'self-search, self-dialogue, and self-discovery' (Moustakas, 1990 p. 11).

Dismissing these and deciding upon EHP was not quite as easy as this sounds. I felt daunted by the challenges ahead. It seemed so interesting, so full of beautifully creative possibilities and 'the way to go' since the revelation inspired by the sandwich, but I knew I was opting for a challenging road and unknown territory. I found the literature to be interestingly written but very complex and it seemed to me that there were not only endless possible ways of progressing this research but that there was also disagreement between authors on the subject and significant differences in the ways in which academics described and structured their work. Finlay (2009a) was helpful in assuring me of the complexity of this research methodology and that I was not alone in my sense of challenge. It was comforting to know that other, very experienced writers and academics 'continue to engage in spirited debate about how to do phenomenological research in practice' (Ibid. p. 7). So, feeling filled to the brim with both encouragement, and at the same time, feeling quite fearful and unsure, I knew I was choosing to set off 'in the dark' and on a journey with no clearly defined destination. This did not feel safe. This methodology was a sketch map of sorts and my walking boots, representing the philosophical tenets, were good for grounding me, but there was no highlighted route and certainly no satnav to direct my path. This methodology was only a guide and it seemed as though there were ghostly

voices behind me suggesting multiple alternative routes all at the same time. I knew though that I just had to go for it and find my own way. This research really is the outcome of that process.

As I reflected upon my growing, co-joined feelings of danger, uncertainty and something near nervous excitement, I imagined this may have been something like Lazarus' experience as he began to emerge from his cocooning shroud, through the darkened tomb, to the hope of day-light beyond (Good News Bible, John 11: 1-44). So, before writing this chapter, inspired by these many reflections and feeling the need to write, but not knowing quite how to begin, I allowed myself to turn to poetry plagiarizing part of van Manen's wonderfully appropriate title *Writing in the Dark* (van Manen, 2002) for my poem *Being In The Dark*.

#### Being In The Dark

With words all around me  
On laden shelves and these  
Bursting-at-the-seams files,  
And with these four wall  
Penning in my horizons,  
I feel I have nothing more to add.  
There are too many words closing in.  
Great words spoken by great prophets  
And yet greater masters  
Seem to have said it all.  
The heaviness of it all!  
Yet, somewhere beyond  
These dim night-scape walls,  
These heavy rain-clouds of words,  
I hope that soon the darkness will lift  
And show me a new horizon.  
And that with its sight, words may wonder  
From paper to brain, and back, embodied  
Again in questioning wonder,  
With re-birthed delight to illuminate  
And order words to their place.

## The Methodological Journey Begins

Phenomenology and hermeneutic systems initially came into being to 'compensate for the losses' and the limitations of the empirical approach, providing other contexts of knowledge (Polkinghorne, 1983 p. 203). Since the early part of the 1900s this quickly became an established philosophy which then rapidly developed into multiple research methodologies which Lavery describes as a field which is, 'one that is continually evolving and perhaps forever on the way' (Lavery, 2003 p. 31). Finlay describes the range of phenomenological approaches as 'rich' with 'many ways to 'do' phenomenology' and suggests there may be multiple ways of categorising and describing it (Finlay, 2011 p. 87). Owen's explanation for this is that 'all knowledge is human made, and not timeless and unchanging' (Owen, 1996 p. 273). However this is done, or whatever the research design, phenomenology will always mean a slowing down, focussing upon and dwelling with the phenomenon, the specific part of the lived world to be investigated and 'making explicit the meanings we attach to our human experience' (Finlay, 2011 p. x). Its aim is not to create theory, or the categorization or explanation of behaviour, but rather to discover more about what it is to be human from people's lived experiences of their world. Husserl's focus was to 'go back to the things of the world' (Finlay, 2011; Polkinghorne, 1983; Macann, 1993; Lavery, 2003) and was the starting point for this research.

## The Chord of Existential Hermeneutic Phenomenology

Designing and writing the following section has been challenging, not only because some components of this methodology are not exclusive to it, but also because it does not have a procedure or process to follow related to a clearly defined method, (van Manen, 1990 p. 29) and can never be a linear process. Because of this there is no obvious starting point for such a section describing these components and further, many of these components cannot be easily described or understood in isolation from the others. Another added complication, as Crotty (1998 p. 1) draws attention to so early on in his

writing, is the fact that authors and researchers in this field use different terms for these components. To help me explain this interrelated, non-linear amalgam, I spent some time searching for a helpful metaphor. The picture of a multi stranded rope came quickly to mind as I had seen this used to help describe a workable framework for research (Dewing, 2011 pp. 68-69) but I found this did not quite offer the sense I was searching for. I also considered the models designed to explain DNA and multi faced three dimensional mathematical shapes with the interior total capacity being EHP and the faces representing its linked component parts, but again neither of these metaphors were adequate. I even considered adapting the various flower diagrams used to describe Kitwood's person-centred ideas (Kitwood, 1997) but this seemed limited by its focal centre point and its too separated petals.

I then struck upon the idea of a chord. This is a musical term used to describe a series of separate but intricately and harmoniously related notes, which 'clothe melody' and are 'simultaneously performed' and are 'woven together' with those preceding and those following. This was a remarkable 'find' and became even more remarkable as an illustration because further reading reminded me that through time the notion of what is an harmonious sounding chord has changed (Scholes, 1964 pp. 251-252). This has certainly been the case with research methodologies, which have come and gone out of fashion over the years. Amazingly the metaphor continued to hold strong because the structure of a chord can be open to artistic variation, with the possibility of one component assuming dominance and with the option of it being played by different instruments to vary its colour. Chords can be short and staccato or tied to other such chords developing its impact and effect. Within a chord the separate notes become almost indistinguishable from the whole, such merging producing the chord's true beauty and colour and the composer's intended sound. What is thus produced under the direction of a conductor, or researcher, is almost indescribable and uncontainable in words, but has to be heard of felt to be known.

I hope this notion of a chord and my diagrammatic representation of the methodology in Diagram 2 will help explain what I have come to understand as the interrelatedness of concepts within EHP a little more clearly. The research process is never a linear process but is instead integrated (Lavery, 2003 p. 28) and,

‘tries to ward off any tendency toward constructing a predetermined set of fixed procedures, techniques and concepts that would govern the research project’ (van Manen, 1990 p. 29).

The following sections represent the components I will be incorporating in my research. To guide me through my thinking, in what I have experienced as the disorientating, foggy landscape of this methodology, I have written in what appears to be a linear, ordered way with sections appearing independent of each other which may wrongly suggest some degree of ordered progressive application. This is not to be understood as such. In keeping with the notion of the chord they should instead be considered interrelated, overlapping and integral to each other and played simultaneously. The following sections are therefore the full, round-sound harmony, with each component taking its place as an essential part of my whole project. This includes sections describing the existential, hermeneutic and phenomenological components, which demonstrates this project’s philosophical grounding, and their methodological contribution with a comprehensive drawing together of all these components to help illuminate both dominant and subtler aspects in equal measure to ensure each can be heard with clarity through the complexity of the whole.

## The Components

### Descriptive and Hermeneutic Components

While many phenomenologists (Giorgi 1985; Colaizzi 1973; Fischer 1974) referred to as the Duquesne Tradition, seek to explore the life-world with the pure, descriptive phenomenology of Husserl, this project follows the Dutch, or Utrecht School of Phenomenology with particular reference to the work of



van Manen and Todres, which combines both phenomenology and hermeneutics in a synthesis of description and interpretation for the exploration of lived experiences (Cohen and Omery, 1994 in Dowling, 2007 p. 138).

Van Manen describes this as 'a search for the fullness of living' in which 'description carries moral force' (van Manen, 1990 p. 12) and that such descriptions need to be full and detailed, rigorous, rich and deep. They are about what is, or might be being revealed in the experiencing and the saying, related to the experiencing (Finlay, 2011 p. 17) and are therefore not descriptions of the phenomenon but are descriptions of the experiencing of a phenomenon. While I hold an existentialist view that my own and others' descriptions will never be identical, I believe that this does not in any way invalidate my own or the others' nor make our contributions less significant for the generation of new knowledge. Other phenomenologists do hold differing views. Marcel for example, believes that an individual description is of little significance by itself, but that shared experiences and the modification of intuition by others can develop a useful social intuition (Marcel, 1935). There are further differences between those whose approach is more scientific, precise and normative, and mine which is more poetic, with the use of occasional flurries of poetry and metaphor to help develop a deeper description and interpretation of the phenomenon. Finlay sees description in phenomenology as less polarised but more of a range 'along a continuum with pure, rigorous scientific description at one end and fluidly poetic interpretation at the other, with most practice falling somewhere in the middle' (Finlay, 2011 p. 19). She and Merleau-Ponty have beautifully described this as the 'intertwining of science with art, the imparting of a poetic sensibility to the scientific enterprise.' (Finlay, 2011 p. 110; Merleau-Ponty, 1945/2012). The middle ground on this continuum is a position which Todres and Galvin (2006) and Todres (2007) support, and I have attempted to achieve in this research, 'where both structure and texture can be attended to' avoiding the possibility of either dry distant accounts or

excessively poetic accounts in which meanings may remain too implicit. Todres (2007 p. 58) uses the terms 'closeness' and 'distance' to describe these poles. By remaining near to the middle ground of these, I believe it has been possible to present all the findings of this research as 'a composite with possibilities' (Ibid.). To this end I have dwelt with the participants' descriptions of their lived experiences and opened myself to the creative, elucidating potential of poetry, and written in such a way to resonate with the participants', the readers' and my own sense of lived life.

Heidegger's view on this subject was that pure description was in reality impossible because, 'What is spoken is never, and in no language, what is said.' (Heidegger, 1971). My research supports this with its three hermeneutic turns.

Its first hermeneutic turn relates to the participants' experiences, which following Heidegger's view, are themselves, to some extent, already their interpretations of the phenomenon. This is because a person cannot stand outside his or her life-world and simply observe it because they are actually part of it and Gadamer says of this that, 'when we interpret the meaning of something we actually interpret an interpretation.' (Gadamer, 1986 p. 68)

The second hermeneutic turn therefore is in my role as the researcher, interpreting the participants' interpretations. To find essences and meanings I have searched 'behind' the words participants have used, to find hidden, implicit meanings and to then bring these, as possibilities, to a more explicit openness (Finlay, 2011 p. 111). This is a tentative process, respectful of the words chosen by the participants and of their right to have their voices heard, but is also one in which I play some part in bringing otherwise hidden essences and meanings to light. I have had no desire to rewrite their stories, just to help find them and to understand their meaning. Anything more than this I believe would be, not only unethical, but also pointless. This research is not about me, nor my story, although it will inevitably take its place, but is

centred on the research participants' lived experiences, in such a way that a meaningful-world-with others (Galvin and Todres, 2009 p. 314) is reflected in my writing. My involvement will therefore be clearly evident, not only from my interpretation of the data, but also from my reasons for asking the research questions that I have, my motivation for this research, the methodology I have orientated towards, the limitations of my reflection and reflexivity, the way in which I am both limited and inspired culturally, by my education, by my historicity, and by the ways in which I have chosen to use the data and present the outcomes of the data. I therefore expect that by the last page of this thesis the reader will not only know more about what is implied in its title, but also that it will have revealed much more about me the researcher. This will be through its interpretive component and will be much more than I have included in Chapter 2 where I described my background and my beliefs and values that have affected its nature and been my sustenance throughout the process.

A third hermeneutic turn very much involves the reader. As you read this thesis you will not be engaging with it bracketed off from your own life experiences or your beliefs and values, and if you are a HCP, perhaps not even from your own experience of person-centred dementia care. You will be interpreting the content of these pages through your very personal life lenses, adding to its creative and re-creative potential.

### The Existential Component of this Research

Existentialism believes there is more than one 'world' which can be studied and as many different 'worlds' as there are people in them, and that it is through the subjective experiences of research participants that we can learn more about the world and the human experience of it. So, existentialist research asks what the experience of something is like for a person, the answers to such questions providing a deeper understanding of the quality, texture and meaning of a particular experience of a particular phenomenon. This requires that the researcher gets as close as possible to the research participants' experience by careful listening, and attempting to look at the

world through their eyes, and feel it with their hearts as far as this is possible. It is specific and personal but at the same time it is also intimately intertwined with the researcher and their world, in the search to understand, with themselves, what is waiting to be said, and through the dissemination of the research, shared with others.

There are of course layers of potential tension in this. Firstly in the way that such research is individual and hermeneutic, involving both the researcher and the participants, and secondly in that, if a person's experience of the world is his or hers alone, the value of such research focussing only on one person's understanding could be considered minimal. Todres, acknowledging some residual, personal tension with this, but referring to the 'master writers' Sartre and van den Berg, confidently asserts the powerful potential of such writing to lead to greater understanding of phenomena (Todres, 2007 p. 7). Todres and Galvin masterfully dismiss any notion of this tension for me by the wealth of insight that they offered with a single case study about the experience of caring for someone with dementia (Todres and Galvin, 2005). I found this paper to be enlightening and extremely encouraging. As a researcher I have learnt much more about the phenomenon I have investigated and been changed by this. This can equally enlighten readers and there is therefore the potential for transferable action as the knowledge generated may be instructive for others (Todres and Galvin, 2007 p. 28). Further, as EHP does not code or classify recurring themes (van Manen, 2014 p. 319) as in holistic-content analysis (Elvish et al., 2014) and with ethnography or grounded theory, and some other phenomenological research (Hansebo and Kihlgren, 2002; Doona, 1995) here I have engaged in 'a free act of seeing meaning' (van Manen, 2014 p. 320). Then, after allowing the free voice of the individual findings to be heard, I have merged all the data into summary essences and meanings and considered what I believe to be possible implications as the phenomenon 'applies generally and typically' (Todres, 2007 p. 7).

Throughout this research I have embraced the tensions highlighted here rather than finding them to be insurmountable or incompatible and see this as providing an opportunity for extending the range and depth of data available for possible new knowledge to be discovered from hermeneutic phenomenology with an existential focus.

### Creativity in this Research

‘Like poetry and song, it grows out of being and reaches into its truth.’ (Heidegger, 1971 pp. ix and 13)

As a fairly recent phenomenon in qualitative inquiry (Prendergast, 2009 p. xxi in Prendergast et al., 2009) poetic inquiry is now a growing area of interest for some researchers (Glesne, 1997; Dewing, 2007; Duggleby et al., 2012; Wareing-Jones, 2012; Schuster, 2013; Collins, 2015; Miller et al., 2015) while ‘sit(ting) uncomfortably alongside their ‘conservative’ partners – seen as the *enfant terrible* of the academic landscape’ (Rapport and Hartill, 2012 p. 18).

My emphasis on creativity has been, to some extent, implied in earlier sections of this thesis, mostly in relation to the expression of EHP being the ‘intertwining of science with art’ (Finlay, 2011 p. 109) and my occasional use of poetry throughout this text. Although this refers more to the idea of blending science with the ‘artistic realms’ of the humanities rather than the actual use of art forms to develop and express findings, it is nonetheless true that research projects can make use of poetry, metaphor and story telling, fine art, cinematography, photography, experiences gained through travel, the study of a novel, visual or graphic arts, new media (van Manen, 2014 p. 31) to express ideas, thoughts, reflections or research data.

Whatever the medium chosen, this must be a natural, expressive means for the researcher to accomplish the challenge of effective communication with readers on both an intellectual and personal level (Halling, 2002). Finlay believes that ‘phenomenologists are required to be attentive to the way we express our findings’ for, unless we are ‘gifted professional writers or artists;

attempting to 'stir sensibilities' may be a step too far' (Finlay, 2011 p. 255). Van Manen says that a 'text is most successful...when readers feel directly addressed by it' and that such a text can bring,

'an otherwise sober-minded person (the reader but also the author) to tears and to a more deeply understood worldly engagement' (van Manen, 1990 p. 129) by stirring 'professional sensibilities' (van Manen, 2007 p. 25).

Here van Manen has singled out the artistic use of written words and their inclusion in hermeneutic phenomenological research. It was this methodology's artistic licence with words, able to speak for themselves, without the need for explanation, which was what initially caught my attention when considering methodologies to address my research questions. Like Ely et al. (1997 p. 136) I considered poetry to be a 'joyful' addition, and so have incorporated *voces theoria*, *autobiographia*, *autoethnographia* and *participare* (Predergast, 2009 p. xxii) throughout this thesis to help express ideas, the data, or situations which seemed to need expression beyond prose and into the poetical. Works of art are recreated, to an extent, each time a new reader or observer takes hold of the work, and even each time the work is re-viewed by a person, the slightly different perspective having the potential for new understanding or insight (Merleau-Ponty, 1945/1962 p. 219). Gadamer refers to this as the 'open space' given by creative language, which can then be filled out by what the writer evokes in the reader (Gadamer, 1986 p. 27). It was this re-creative potential that was a further encouragement to me to include poetry throughout.

In recent years, and mostly when I have felt overwhelmed by life's experiences, I have craved the sort of space that comes with slowing down and the feeling of an in-breath (Todres, 2013 p. 146). At such times I have found myself writing brief words, and experienced these then growing into something resembling poetry. This is usually after further reflection on an experience, or picture, or person that has grabbed my attention and on which I have been drawn to wonder. From this, words and images will often flow in

some creative torrent, though I have never been able to force this. It just happens. Knowing that I would not be able to write to order, but only when inspired to do so, was a reason for some of my initial apprehension in taking up this methodology. I would never be able to rely upon such creations. I envisioned endless blank pages awaiting their inspiration.

Similarly, when I have felt the need to explain something in a clearer way, I have found the use of metaphor useful. This sense of finding new words and pictures to enhance clarity or to explain the meaning of something in a new way has been natural to me. Again this seems to spring from some creative well and just takes on its own direction. It seems that searching for appropriate metaphors makes them usually remain rather more illusive.

Loftus et al. describe this openness to creativity in qualitative research as 'exciting' and to be something that we should use to 'open up our understanding of the many ways in which humans engage in living practices' because, they say, 'to think means to be creative' (In Higgs et al., (Eds.) 2011 p. 10). While this is very compelling, I rather prefer Wilkinson's ideas of poetry being 'a creative servant of life' (Wilkinson, 2009 p. 236) and Finlay's ideas of the communicative power of research, 'that challenges, unsettles and reverberates, that strikes a chord with our everyday experience of life' which she says is particularly when 'research turns to poetry and literary references' and that by this 'aesthetic phenomenological writing turns reading research into an experience in itself' (Finlay, 2011 p. 121). Perhaps John Keating in *The Dead Poet's Society* sums this up most accurately for me when he says to his students that,

'We read and write poetry because we are members of the human race, and the human race is filled with passion and this is what we stay alive for.' (Touchstone Pictures, 1989)

An encouragement to trust myself to the use of poetry came to me quite recently when I realised that my poetry could be a 'creative servant of life' which most certainly 'challenged and unsettled' me. Some time ago when

listening to a former soldier talk of his experiences of death and mourning in Northern Ireland in the 1980's, and feeling within him, and then in transference to me, something of the full-blown embodied bombed out person he was too, I found I just had to write. When reading this poem myself to someone who has been tutoring me in creative writing, I found myself welling up and struggled to read it aloud. My own writing had touched my heart as though I had heard it for the first time. Looking up I saw an 'otherwise sober person' also turned to tears before me as he listened to *They Stood By His Grave* (Appendix C).

Poetry however, cannot say it all or in a way something may need to be said. Romanyshyn suggests that language 'can only infer a reality that remains invisible and illusive', which is his explanation for the sense of 'woundedness' felt by some researchers (Romanyshyn, 2013 p. 42). To some extent I believe this must be the nature of EHP research, even that which is not confined by prose and conventional meanings of words and can appeal to poetry and metaphor, free from the usual limitations of grammar and punctuation. I accept its limitations but also continually wonder at its deep, heart-wrenching potential.

### The Lived Experience Component

Central to this research is the concept of lived experience. Its concern is the world as it is experienced, rather than as objectively studied in science from a point or place beyond the immediacy of what is being studied. The purpose of researching lived experience is to clarify things of life's experience which might otherwise be taken for granted or even ignored or go unquestioned. It demands therefore a slowing down to dwell with, to listen to and to focus on the phenomenon, which in this research is the experience of person-centred dementia care for nurses. It begins as something that is understood implicitly, which Merleau-Ponty calls sensibility (Merleau-Ponty, 1968 p. 214) and Dilthey as the 'flow of living and experiencing life's breath' and the 'breathing of meaning' (Dilthey, 1985 p. 59). Because this is immediate, any reflection on it then makes the experience of the past, but it is this which puts it within



grasp to be described reflectively and from which essences and meanings can be found, achieving the aim of 're-achieving a direct and primitive contact with the world' (Merleau-Ponty, 1962 p. vii). Lived experiences then relate to others in a system of contextually related experiences.

### The Search for Essences

When in research the term 'essence' is used, related to the phenomenon, this is asking what is it that makes a thing what it is, without which it would not be the thing itself? Van Manen explains this by stating that,

'The understanding of some phenomenon, some lived experience, is not fulfilled in a reflective grasp of the facticity of this or that particular experience. Rather, a true reflection on lived experience is a thoughtful, reflective grasping of what it is that renders this or that particular experience its special significance.'  
(van Manen, 1990, p. 32).

Initially, I found this an extremely complex concept, which left me wondering what it really meant, until I struck upon the idea of trying to simplify it. Instead of asking about the essence of person-centred dementia care for nurses, I asked myself to consider, what was the essence of Skype for me? A little different! I could describe a Skype call as a means of communicating with people both visually and with sound, usually by means of two screens, and some technical systems (I will never understand) that link the two. This would be a relatively accurate description, but it's my experience of Skype, not this description, which holds its phenomenological essence. For me Skype is my way of feeling physically connected to people, involving a leap of my heart when I see them 'in' my study! From this experiment the dim mirror began to clear and I could start to understand what could arise out of the data to become the essence of person-centred dementia care for nurses. Like van Manen, I had become 'less interested in factual status' but rather more interested in, and hopeful that, by the 'authentic productive linguistic gathering' (Todres, 2007 p. 28) and reflection upon peoples' lived experiences, I would discover more about the nuances and the style of

person-centred dementia care for nurses in Jersey, rather than a 'fixed core' (Finlay, 2011 p. 127).

### The Search for Meanings

The aim of an existential hermeneutic phenomenological description is to elucidate lived experience, and then to intuit implicit meaning by unveiling and exposing what may be hidden in layers of literal words, jargon statements or possibly from the embodied silent expressions of research participants and researchers alike whose bodies may express themselves more overtly than their chosen words. The researcher then has the intention to communicate something that may not be directly expressed by the research participant, as a collaborative intersubjective search for meaning. Interpretation therefore is essentially intertwined with, and necessary for the search for meaning, another concept I found to be initially quite difficult to grasp, until this very simple illustration came to my attention. My daughter was talking to my son's partner about a recent visit to a spa hotel. She said "Oh Sarah, you'd really love it there!" What I understood by this, but not directly 'said', was that because *she* had really loved the experience so much she was sure Sarah would too. My daughter then said, "*Even* the shampoo was so nice I didn't leave it there". From her emphasis on '*even*', supplemented by a broad smile orientated towards her boyfriend, I also knew that she was saying a massive public 'thank you' to James for giving her a gift she really appreciated and understood to be an expression of his care for her. She did not use all these words as I have done, but all this was her meaning, around-and-about the words and with her body's expression.

I then considered the concept of meaning further by asking myself the question, what being awarded an MA degree meant for me. This was not asking what an MA degree was, or for a list of associated feelings related to the experience, but rather, I was asking, what was the 'so whatness' of the award for me. I was surprised by the words and then the meanings I found, not previously having been aware that so much was there but veiled by the

opaqueness of the pre-reflexive, the taken-for-granted, 'seamless stream of living' (Todres and Wheeler, 2001 p. 3) that had not yet become a phenomenon, to be 'questionable and enigmatic' (Ibid.). After reflecting on the unexpected discovery of these newly unwrapped and revealed meanings, together with those of the spa example, I was pleased to see such clear evidence for the potential of this PhD research to unwrap new layers of meaning for nurses' experiences of person-centred dementia care in Jersey.

## Silence and Creative Space in this Research

### Silent Creation

With only a half-made world  
In his hands  
There was silence...  
And there was the darkness,  
So full of potential...  
Creation on hold...  
The creator's creative space?  
Holding time, waiting?  
More glory in the making?  
A womb, a waiting space for wonder?  
Perhaps so, for  
From such gentle reverie.  
Sprung you and me.

I know about creative space. The best of mine is usually my bathroom, first thing in the morning. I do not know why this should be so, but I do know its silent value. I always keep a notebook and pencil there, at the ready. Spiegelberg (1982 p. 693) says that 'Phenomenology begins in silence' and Loftus et al. (in Higgs et al., 2011 p. 10) say that creating space is central to creativity. Romanyshyn believes that, within this space there is the need to let go of the conscious relation to the work. By doing this he believes that the threads that tie the researcher more subtly to the work can have their voice heard in the silent space created by this letting go. He describes this as the 'ritual space of reverie'. I loved this idea so much that, in my own silent (if not quite ritual) space, I found myself holding onto this thin thread and from it came the reflection I have included above. I wondered, did the great Creator

himself make use of such ritual space? Did he embrace such 'epistemological silence'? (van Manen, 1990 p. 113).

This has become an increasingly more significant part of my methodology and through this I am aware that the unconscious sense of the work has had a chance to speak and I sense it has been an important time also for my own personal growth and development. I have discovered a renewed sense of mystery from this reflection which is gradually melting this 'tough-minded researcher' and by so doing allowing something of my 'tender heart' (Romanyshyn, 2013 p. 141) to control the beat of my heart and this research. This has meant a need to let go of so much and allow some sense of vulnerability into this work. This is something of the growth about which I wrote. While the 'tough-minded researcher' within this silent womb space is sensing change, I have also become increasingly aware of a sense that I am surrendering this work to another and in so doing I am not 'shouldering the burden of being its author' (Ibid.) alone. This is a very personal and continuing experience that I have incorporated into this work's methodology, and without which I am confident would have led to different insights and emphases in its outcomes.

### Openness in this Research

Openness to the phenomenon is essential and 'a sustaining motive of all qualitative inquiry' (van Manen, 2002 p. 237). This attitude I believe comes from humility, acknowledging that the world is not only vast and full, but that if one chooses to look on it from another perspective, a different world picture could be seen, as it would be if someone else was observing from my perspective. The phenomenon needs to be carefully examined from every new perspective, taking nothing as familiar, so that new understanding and insight may be found. Polkinghorne says that there is a 'commitment to examine all phenomena carefully and to take none of them as familiar or understood' (Polkinghorne, 1983 p. 43).

To help explain this I will briefly describe a fascinating television documentary I saw recently. It was about vultures. The presenting journalist began with his, and indeed my own, familiar ideas about these scavenging, disease-spreading, bloodthirsty, ugly creatures, but ended his documentary with these very powerful words. 'When I see them now, their character, design, flair, their swagger, I see beauty' (BBC 2 Documentary (01.02.2014) *Vultures – Beauty in the Beast*). This journalist had been open to his world. It had certainly grown considerably bigger and certainly more colourful by his openness. He had gained new knowledge and from his exemplary research, and with his beautiful, creative presentation he had made this new perspective available to me. By maintaining a sense of openness throughout this research I believe my understanding has been transformed by looking through the wider lenses of the research participants as they have shared their experiences for person-centred dementia care from their perspectives. As I watched *Vultures – Beauty in the Beast* my knowledge of vultures was radically altered. I hope that those reading this research will similarly find new knowledge from within its pages.

### Immersion

Immersion and openness are closely related and equally part of this methodology. To help make this concept of immersion clearer, and distinct from openness, I considered the sea around this small island of Jersey where I live. I can learn a considerable amount about the sea by reading books and even by observing it from my car, parked right by the sea wall and can be truly open to its 'more' in this way. However, it is only by stripping off my shoes and clothes and walking across the sand and then by getting into the water that I will know what its saltiness actually tastes like on my lips and know about its power by the feel of the waves and currents pulling me along and of its temperature by my shivering. This is the nature of immersion that has been part of this methodology and through which I have learnt more about the experience of person-centred dementia care.

## Attention to the Body

The philosophical principle of people as embodied beings is a development of Husserl's idea of intentionality. Husserl used this term to describe people's continuous and active orientation towards the world, making us therefore always conscious of something. Heidegger developed this idea away from the dualities of subject-object he saw with intentionality, to the idea of being-in-the-world, his emphasis being a closer *in* the world as an embodied part of it, rather than Husserl's more distant 'towards' the world. Merleau-Ponty developed this idea further from Husserl's 'towards', and Heidegger's 'in' to his own being flesh 'of' the world with 'a reciprocal insertion and intertwining of one in the other' (Merleau-Ponty, 1964/1968 p. 138). In this research the concept of flesh of the world is important in two main respects, firstly, in the very obvious joining of the participants' worlds and mine through our embodied meeting and thus 'fundamental intertwining' (Finlay, 2011 p. 37) as flesh of the same world. Secondly, I wanted to discover more about the participants' experiences of their intertwined flesh of the world relationship with person-centred care through their lived bodies, and of their closeness or distance, intimacy or separation (Todres, 2007 pp. 165-166) with the phenomenon, by means of their redirected gaze back to their experiences of it.

Such enquiry 'focuses on the basic embodied connectedness with the world we live in' (Heß, 2012 p. 26), this reflecting my personal beliefs and being an essential part of my practice for ten years. I believe that the body is integral to any understanding of the human situation (Finlay, 2011 p. 36) and because of this I have readily adopted Gendlin's ideas of a 'body which speaks and knows' (Gendlin, 1978) into my work and more recently been inspired by Merleau-Ponty's ideas of people as embodied beings (Merleau-Ponty, 1945/1962) and Todres' application of Merleau-Ponty's and Gendlin's ideas to embodied phenomenological research methodology (Todres, 2007).

Todres' starting point is also van Manen's of,

‘taking up of a certain attitude and practicing a certain attentive awareness to the things of the world as we live them rather than as we conceptualize them’ (van Manen, 2000 p. 460)

which he calls the ‘basic method of phenomenology’. Todres develops this by saying that ‘fresh sense-making occurs as a bodily experienced recognition’ of the ‘unsaid life of the phenomenon’ with the body being the ‘messenger of the unsaid’ (Todres, 2007 p. 28, 27).

It is true that we tend not to notice our bodies, apart from perhaps when they are damaged by illness and we are in pain. In this case our bodies cry out for attention (Merleau-Ponty, 1945/1962; van Manen, 1998 p. 11). This is like the situation with our cars. We drive off in them and think nothing more of them until they break down or we are reminded by a shrewd mechanic that they might benefit from a service. As researchers we will get much more mileage from our work if we learn to listen to the subtle messages our bodies give us. I have endeavoured to incorporate such attention from the formulation of my research enquiry, to how I have dialogued in research interviews and how I have then allowed my body to give up its evidence in the radical reflection of texts and how I have explored ways of communicating my research findings. At the point of this research being read by others, it is my hope that my writing will touch the depths of the sensing body of the reader so that they are brought nearer to an enriched understanding of the phenomenon, not just with intelligence ‘limited solely to the mind but also tied to the body’ (Merleau-Ponty, 1945/1962).

In this there has also been an inter-corporeal component, from the experience of just being with research participants, to listening to, engaging with, seeing and feeling their embodied experiences, and in some cases, extended to their reflections on their own body speaking to them, speaking to me. This dance is something I occasionally experience in my counselling

work and was delighted to experience in the interviews and later, with deep radical reflection, I was able to tune into the music again, as if once more in the participants' physical presence, listening to them speaking and re-experiencing this entwined, inter-corporeal movement. Lala and Kinsella say that such inter-corporeality is an everyday life-world experience, and that this 'mutuality of our embodied subjectivity does not turn off in the research context' (Burns, 2003; Lala and Kinsella, in Higgs et al., 2011 p. 82). In summary Cornell says that 'what is bodily felt, actually has more practical value than all the clear, well-articulated thoughts we may be thinking, and is the direct source of creativity' (Cornell in Gendlin, 1978).

### The Humanising Component

EHP requires 'that the researcher stands in the fullness of life, in the midst of the world of living relations and shared situations' (van Manen, 1990 p. 32) and by such a stance we come to understand more of what it means to be human in all our fullness in the world. In this there is no screening of emotions, no recourse to numbers and quantifiable data, so that the real issues that need attending to can be known (Dewing, 2009 p. 232 in Froggatt et al., 2009).

Throughout this project I have fought to hold onto all that is me and battled to let go of any wily or artful demands of my ego to ensure I do not get caught up in a fight to appeal to those academics who may require alternative methodologies or philosophies for insightful meaningful, rigorous research. Throughout this work I have nurtured my human presence and have also aimed to bring to the reader's awareness the very real human nature of the research participants' lived experiences and their earthy, everyday humanness in their lived human worlds.

### Wonder in this Research

I have, for as long as I can remember, been drawn to wonder about anything that has come my way. To find this to be an essential component for my



research was a pleasant relief as some of the other components seemed to be so much harder to understand, and therefore to incorporate within the research methodology.

Wondering about my experience of work as a person-centred counsellor and how this may or may not relate to person-centred dementia care was something that seemed to take hold of me until I was filled with curiosity. This became an early motivator for this research, which van Manen describes so well for me in the following.

‘Wonder is the unwilling willingness to meet what is utterly strange in what is most familiar’ (van Manen, 2011)

and this for the purpose of shattering our taken-for-granted views of the world.

‘Embracing an attitude of wonder can involve a kind of ‘epistemological earthquake’ where we, ‘arrive at the world as if for the first time...The more we reflect and wonder - the deeper the wonder seems to grow and the more enigmatic the world and life seem to be.’ (Hansen, 2010 p. 172 in Finlay, 2011 p. 231)

Because this has been my experience from the earliest days of this research and for many other life experiences, I have included my poem *Cathedral* as this expresses something of this component of wonder. I wrote this after visiting Ely for the first time. It was a misty day. The first sight of the city was of the cathedral rising up across the flat Cambridgeshire landscape. I experienced an almost uncontainable sense of wonder, totally ‘felt’ and without words. Time then did its work, moulding my embodied experience into words, leading me into my questioning. Unlike its formless beginnings these could be caught, inspiring *Cathedral* (Appendix B).

### Bracketing, Reflexivity, Reflection and Radical Reflection

To bracket or not to bracket? That is the question.....which appears to be the source of constant debate amongst phenomenologists and is one of the first to consider once phenomenology has been selected as an appropriate

research methodology (Finlay, 2009a p. 11). It appears that most researchers do accept that their subjectivity is inevitable and is actually what characterises phenomenology and I wholeheartedly agree with Giorgi that 'nothing can be accomplished without subjectivity, so its elimination is not a solution' (Giorgi, 1994 p. 205). There also seems to be agreement that researchers should adopt a 'phenomenological attitude' and strive to be open to see the Other 'freshly' with 'disciplined naivety' (Ibid. p. 12). I did not like the idea of 'striving' to be 'open to the Other'. I imagined that, with the way we tend to screw up our eyes and squint as we try to focus on objects outside of our comfortable visual range, I might, by doing this, unintentionally distort the phenomenon and make it less 'visible'. Instead the phenomenological attitude I have incorporated in this research is wide-eyed and involves less strenuous effort.

The debate seems to heat up from here though as researchers struggle for agreement on what they should then do once researcher subjectivity is accepted, though the need for a phenomenological attitude is agreed upon.

Bracketing, also known as the reduction, although previously unfamiliar to me by this name, was not so as a concept. This had come to my attention during my counselling training, most of which was Humanistic, Person-Centred, based on the theories of Carl Rogers (1902-1987). Because of its importance to my professional practice and because it shapes some of my deeply held beliefs, I have written about this in Chapter 2 and also in Chapter 4 where it forms part of my philosophical discussion. Here my concern is for its significance to my methodology. While most person-centred counsellors would say that they 'bracket' themselves and their beliefs and values, cultural ties, opinions and judgements off before entering a counselling session, to enable a non-judgemental openness to the client's world, unencumbered with their own, I had always struggled to accept this theoretically, believing it to be unattainable in practice. Furthermore, as a person before another, with all my own brokenness and subjectivity clothed with an empathic heart, and

not a logical, binary speaking computer screen, I believe I am thus able to come closer to others. Although the idea of bracketing did seem so philosophically appealing and would be so helpful methodologically, as with my counselling work, just 'how to convert this philosophical method into a practical empirical one' (Finlay, 2009a p. 18) remained impossible. Van Manen confirmed this for me by saying that phenomenological research 'is always a project of someone: a real person...who, sets out to make sense of a certain aspect of human existence' (van Manen, 1990 p. 31).

Another related issue was my belief that it is impossible for a researcher to stand outside the lifeworld and observe it from a distance, which also seemed to be called for with bracketing. It seemed to me that the fact that a researcher takes up a project in the first place indicates they are already established in their research participants' worlds. I knew I was inseparable from these and I would study them from within (Polkinghorne, 1983 p. 240).

So this left me at a place within the research participants' worlds where I knew my subjectivity was a necessary part of my research and that I could not bracket myself out. So, like van Manen, Gadamer and Heidegger before him, I have not attempted to 'bracket' myself out of this research but have sought to differentiate and draw attention to what belongs to me in the work from what belongs to the other and the research itself (Romanyshyn, 2013 p. 349). Gadamer summarises my own attitudes well and how I have explored these in this research.

'This kind of sensitivity involves neither 'neutrality' with respect to content nor the extinction of one's self, but the foregrounding and appropriation of one's own fore-meanings and prejudices. The important thing is to be aware of one's own bias, so that the text can present itself in all its otherness and thus assert its own truth against one's own fore-meanings.' (Gadamer, 1975 pp. 268-269)

In this research I have aimed to engage in honest self-aware reflexivity and reflection from the start, with Chapter 2 focussing on my beliefs and values, my cultural background and the experiences of which I am aware, that colour

the lenses through which I experience the world. I have attempted to be constantly aware of their potential to influence and distort the participants' voices throughout, through reflection, reflexively and with radical reflection (Merleau-Ponty, 1945/1962 p. 219; Dewing, 2011 p. 73).

Because the dividing lines between these definitions has sometimes seemed very fine, or interchangeable, or inseparable, something like sea currents in one ocean, I have embraced a 'fluid, dynamically paradoxical' flow between bracketing, reflection, reflexivity and radical reflection and my 'lingering pre-understandings' to exploit them as,

'a source of insight; between being empathically, and naively open and self-critically aware; between detaching from lived experience and being involved with it' (Finlay, 2011 p. 82)

and being carried along in the flow. In this endeavour I have been encouraged by both Schaffer (1912-1984) and Romanyshyn. Schaeffer writes that,

'People have presuppositions, and they will live more consistently on the basis of these presuppositions than even they themselves may realise' and that these 'rest upon that which a person considers to be the truth of what exists.' (Schaeffer, 1979 p. 19)

Romanyshyn believes this adds to the 'researcher's woundedness' because although the intention is to address biases, they know much may remain hidden even from themselves (Romanyshyn, 2013 p. 209). I have felt this sense of woundedness throughout the research process. I know that what I have heard and written about is undoubtedly written with my accent audible throughout. But, I am also comforted by the sure knowledge that if I had not listened and written as I have done, these words, no matter with whose accent they are 'spoken', would never otherwise have been heard. They carry new understanding.

### Embodied, Relational, Attentive Listening

Although interviews are not the only means of data gathering in phenomenological research (van Manen, 2014 p. 31) they are often woven into phenomenological researchers' methodologies (Finlay, 2011 p. 198) and here I have used semi-structured interviews as a means of hearing the voices of the participants describe their experiences of the phenomenon. I chose semi-structured interviews because of the freedom this would offer participants to voice what they considered to be significant descriptions of their experiences and not be reigned in by my expectations for content. The interview process and the stages following these are described in more detail in Chapter 6, including immersion into the participants' lived experiences through reflection and radical reflection of the texts, reflexivity and moving back and forth from specific elements of these to the whole texts, referred to as the hermeneutic circle, used specifically for the purpose of finding essences and meanings. I made every effort to make the interviews welcoming, offered the participants space and time to tell their stories, and always attempted to listen, facilitate, and be aware of their responses. By the intertwining of our embodied selves as researcher and participant in this way, I felt absorbed into the Others' experiences and through I-Thou relationships (Buber, 1937/1953) was thereby enabled to 'listen to the worlds they inhabit' (Williams, 2005 in Hughes et al., 2006 p. 27).

Buber beautifully describes such a process as part of 'natural creation',

'with a gradual selective progression from experiences to thoughts, from thoughts to words, from words to writing and from writing to public communication.' (Buber, 1957/1974 p. 8)

### Hermeneutic circle

The idea of the hermeneutic circle, first named as such by Dilthey (Polkinghorne, 1983 p. 227) is closely related to both interpretation and the search for meaning from the embodied-being-with the participants in the interviews and with immersion and radical reflection on the transcripts of these. When translating a text from French to English, I cannot go about this

word-for-word, simply translating each in turn, nor can I rely upon a thesaurus to give me the correct alternative word. What may be given in a list may not be the correct meaning in the context. Only by knowing something about the author, the context of the whole text and the place within this, does the right word fit and the intended meaning hold for both the word and the whole text. So, with the hermeneutic circle,

‘the interpreter gains understanding by grasping the meaning carried by the linguistic articulation of the text’ (Ibid. p. 226)

with the fusion of horizons between the participant’s and the researcher’s worlds and movement between the parts and the whole text which continues until a clearer understanding of the meaning of the text is reached. Finlay extends the hermeneutic circle by describing it as,

‘the process of coming to understand the being of something (be it a ‘text’ or the ‘phenomenon’ or ‘participant’ in the research context) through moving iteratively between the whole and parts and back again to the whole.’ (Finlay, 2011 p. 115)

I have incorporated this in my methodology to encourage as much new understanding to be ‘nudged into being’ as possible (Ibid.).

## Writing

‘Paper thin, the paper weighs nothing. The words slowly weigh it down, and page by page, the heaviness transfers and shifts, yet I don’t become lighter: there is more. More to breathe, more to feel, more to birth, more to penetrate.’ (Milloy, 2005 p. 546-547 in Finlay, 2011 p. 17)

I have included this quote because this has been my own experience of writing since the earlier days of *‘Being In The Dark’*. This mighty task with a life of its own has grown and ‘ordered its words to their place’ but yet more have taken me over. I think with the sounds of words and the pictures drawn by them so much so that words are living in me and I in words, with meanings chiselled out with punctuation, grammar and tone, though sometimes discarded altogether.

Writing has been an essential component of the methodology for this research. By writing I have come to a better understanding of its philosophical groundwork and the methodological components, and as I wrote and rewrote the texts I searched for new insights and for better ways to communicate these effectively to my readers at both an intellectual and personal level (Halling, 2002). What really motivated me though was idea that,

‘textual emotion, textual understanding can bring an otherwise sober-minded person (the reader but also the author) to tears and to a more deeply understood worldly engagement.’  
(van Manen, 1990 p. 129)

By drawing others more closely into the lived experiences of nurses’ person-centred work, it has been my intention to bring the reader to this more worldly engagement and a better understanding this phenomenon (Ibid. p. 128).

More modern writers accept that the style a writer uses derives from their embodied being and their contact with the world (van Manen, 1990 p. 132) and that it is a blessed moment where style gathers language to,

‘suddenly swell with a meaning which overflows into the other person when the act of speaking (or writing) binds them up in a single whole.’ (Merleau-Ponty, 1964b p. 235)

I have known the power of both poetry and song to touch me soul to soul with another, even though I may never have grasped the whole or intended meaning of the poet or composer. Sometimes what hovers around the words can say even more than the words alone and speak to me in clearer tones than were ever imagined. This I believe is creativity at its best. It is where pictures are painted without a brush and melodies are heard without a voice. When I have felt inspired to write but too hemmed in and confined by the conventions of grammar and punctuation, I have turned to poetry and metaphor in this research. This is,

‘that place which is beyond the concrete world’ where, ‘through its appeal of our emotions and empathy, poetry brings into focus those

slant truths that lie to the side of our vision' and can 'provoke different questions in us from those that are posed elsewhere' (Zeilig, 2014 p. 172-173).

Such writing, I believe can accomplish the task of 'showing' us rather than 'telling' us about the world.

### The Missing Component

It may seem rather strange to be ending this section by joining with the ranks of other existential hermeneutic phenomenologist in a mood of mourning, (Romanyshyn, 2013 p. 4) but I now understand this to be an essential component of this methodology. I know that the depths of my unconscious are fathomless, that there will always be other words to read and write, other perspectives from which to look, and higher peaks to climb, another road to explore, other pools for refreshing, and that my body will be holding onto more (Gendlin, 1992 p. 4). So, when the last of the ink is dry and the last page turned, I will want to travel a little further, towards a more distant horizon. The missing component will remain and leave its haunting, calling echo.

Writing this poem *When All Is Said And Done* has helped me to express what I know to be the limits of this research to its place and within its time, the depths I have not been able to explore and the body which has not been able to 'say all this once and finally' (Todres, 2007 p. 27; Gendlin, 1992 pp. 1-8). With this creative approach to understanding (Laverty, 2003 p. 28) I know, you the reader, must 'listen in vain for the punch line' (van Manen, 1990 p. 13) but it is with such a creative methodology I hope that you might hear something of 'the voice in an original singing of the world' (Merleau-Ponty, 1973; van Manen, 1990 p. 13) and discover more.

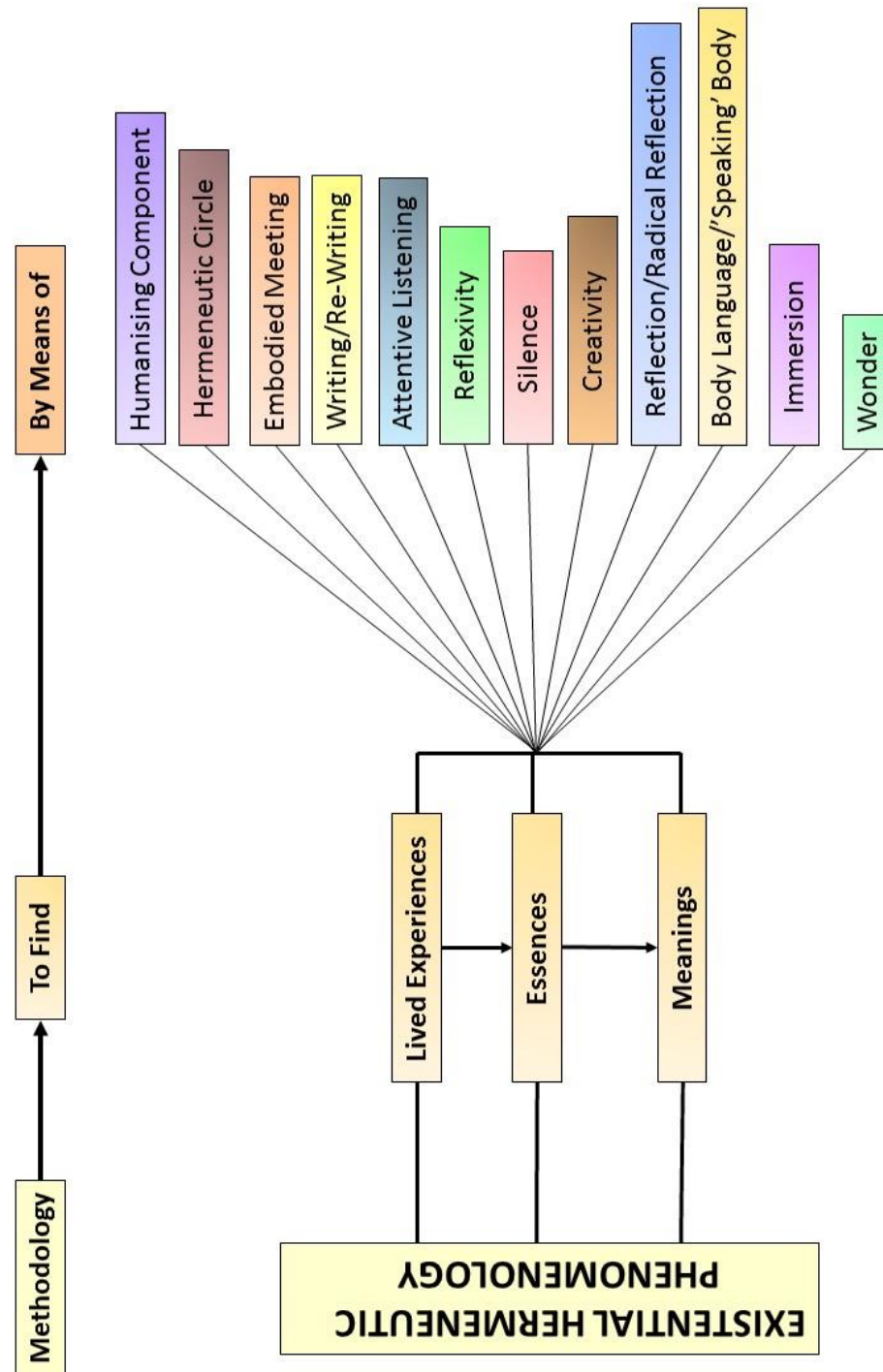
### When All is Said and Done

You have heard it said,  
That cliché of old,  
'When all is said and done'.  
But can it ever be,



When the journey's over,  
The destination reached,  
That was its all?  
That it was complete?  
Or, could it be,  
If I turned, and gazed,  
Re-orientated,  
By fine degree?  
Or changed the lenses  
Of tired eyes?  
Or ask another their story?  
Or return another day  
Turning back time's tide?  
And re-live?  
What then?  
Would I see  
Something I missed?  
And then know life's finer detail?  
And with renewed confidence say,  
'All is truly said and done.'  
And then rest my head  
On pillows  
Belonging to the divine  
And chance to hear Him say  
'It is finished?'

Diagram 2: The Methodology for the Research



## In Summary

When just the phantom, the body-less nature of this work existed only perhaps somewhere deeply cocooned in my subconsciousness, wonder was there, stirring what could be. It has become the tonic note upon which, not only this methodology, but also the entire thesis is built. As the work began to assume its living reality in me, I took hold of its creation in my hands, taking on the awesome responsibility of re-creating the primal sounds of lived experiences, through the methodology, using the clef and stave of existential hermeneutic phenomenology on which to form the music you hear. The tempo is unhurried, played in a reflective mood with notes having been appointed to their creative places on the stave. At times in its playing, it has seemed as though the sound has diminished to the barely audible and then crescendos again as silence and sound have taken their places.

Essentially, music touches our hearts and souls and minds, entwined together in our embodied being. It is a living experience. But before it can be played and heard it has to be written down. This is our access to the music. What you hear though is not the soundtrack, the original playing in the composer's head. Instead the manuscript has entrapped, restrained and contained the music by its written form. Likewise this research exists to be shared, to bring new life, new understanding and knowledge to the reader, but it cannot say it all. Communicating will always, to some extent, be confined by the limits of an artist's skill or palette or manuscript, or by language and words, or by the reader's interpretation. And so, in a sense, the mourning begins for me as the darkness overshadows it to some extent. But I am not in full, black mourning. This research can live on in its words and for its time: 'all is not said and done'.

So, from wonder, all the components of this chord have taken their place and will continue to be doing their work. While not all of these will be explicit in its reading, what will be evident throughout, giving its very distinctive style, will be the following five components, linking its philosophical roots, its

methodology, its method and data analysis. Throughout this research you will be aware of,

1. It being explicitly existential, describing personal lived experiences and making no reference to recurring themes, grouped data, n= numbers, charts or graphs. It will articulate 'unique variations of experience'. (Galvin and Todres, 2013 p. 31)
2. Its movement from natural science with its search for theory to explain and control the world, towards the humanities, to bring plausible insights and offering direct contact with the world. There will be no 'final and conclusive law-like absolutes' (Ibid.).
3. Its interpretation of the texts.
4. Its use of reflexive engagement of self throughout.
5. Its use of the artistic component of poetry and of metaphor.

These components together have provided a methodology (Diagram 2) that has been both an extraordinarily helpful guide for every aspect of this project and has added colour to my original sketch map (Finlay and Evans, 2009 p. 13). They have assisted this traveller on her journey from 'Philosophy' to structuring a 'Method' and for the onward journey to its 'Eventual Destination' the place of haunting echoes, whispers and song.

## Chapter 6

### Creating a Pathway: Method



## Chapter Six: Method

### Creating a Pathway

‘Everything here is the path of a responding that examines as it listens. Any path always risks going astray, leading astray. To follow such paths takes practice in going. Practice needs craft. Stay on the path, in genuine need, and learn the craft of thinking, unswerving, yet erring.’ (Heidegger, 1971/1975 p. 186)

Previous chapters have been dedicated to presenting my personal ontological stance, reviewing my research field and outlining the philosophical tenets underpinning this research with its related methodology. These have provided a way for me of looking at the world that is authentically grounded and has provided a congruent epistemology. In this chapter I am now turning my attention to the method. While method in research may be described by some as the ‘techniques’ and ‘procedures used to gather and analyse data’ (Crotty, 1998 p. 3) I see this more like a path or a backbone: the central, supporting structure for this research, which has grown within its body and which carries its central nervous system to generate data from the encounters, dialogue and reflection (Finlay, 2011 p. 197). This method therefore prioritises the sharing of individuals’ experiences through the embodied being-together of researcher and participants in interviews with the continuation of these relationships through the transcripts and of further intertwining in co-created interpretations of participants’ experiences.

### Introduction

The word method, first used in the 16<sup>th</sup> century for the study of natural sciences, and from the 19<sup>th</sup> century in social sciences, is now often thought of as a set of procedures designed by specialists, to ensure the objectivity of results, to limit researcher biases and to allow other researchers to check the accuracy of the results by following the same procedures (Romanyshyn, 2013 p. 205, 209). As I have discussed my research with others there has been some presumption that this was the type of research I was doing

although there are of course many different methods that researchers use to discover new knowledge and understanding. Within phenomenological research different methods are employed with some, like Gadamer, believing that scientific methods cannot lead to 'true' understanding (Gadamer, 1975/2013) with his hermeneutic phenomenological method bearing very little resemblance to this. Romanyshyn is in agreement, saying that it is necessary 'to erase the erasure of the presence of the researcher in research' (Romanyshyn, 2013 p. 209) and argues for the inclusion of the 'unconscious depths of the researcher' along the path 'from the place of not knowing one's topic to the place of coming to know it' (Ibid. p. 215). Because the researcher's subjective, creative presence is very much at the heart of such research, researchers must remain open to the possibility of being struck by the wonder of something new, or of hearing and experiencing an older, more familiar song being sung with a new voice or to a new tune. This must be so in every stage of the process including the creation of its method with the outcome that methods can never therefore be replicable, predetermined or prescribed, but always guided by the researcher's openness to the new and perhaps the unexpected.

Van Manen continues this theme by saying that,

'Phenomenological method is always a matter of attempts, bids, and hopeful risks. Within a phenomenological context, method is never just an engine that will unerringly produce insightful outcomes.'  
(2014, p. 29)

To achieve this he highlights the need for the researcher to be guided by 'interpretive sensitivity, inventive thoughtfulness, scholarly tact and writing talent' (van Manen, 1990 p. 34). I certainly questioned whether I had these skills at the required standard and for some time believed this may be too much to take on. However, it also seemed I was being goaded or enticed by another voice calling me into this, with the offer of an adventure into the unknown, which I found I could throw myself into when it seemed to meet up

with my growing passion to go beyond these voices to 'hear the voice of matter itself' (Hansen, 2010 p. 163).

### The Development of the Research Method

This chapter describes in detail the methods for this research, which, true to van Manen and Romanyshyn's statements above, involved not simply the application of a given process or a fixed set of procedures. I remained open to changes and amendments along its way and it was therefore an emergent, creative process with very few directional or distance signposts, and with no programmed satnav system set for the journey. Instead I often had the sense of being something of a lone traveller, a wondering wanderer and pioneer, having to find my own pathways. This also felt, at least initially, as though I was setting off into the night with only the pale moonlight of my research questions illuminating the vocative, whispering landscape of the methodology. It did feel risky, but less so as I gradually became aware that the moonlight and the landscape had merged together which seemed to deepen my confidence and invigorate my passion for this project. Pathways became clearer and the project took on some tangible form.

Following on from van Manen and Romanyshyn's introduction to phenomenological research method above, Finlay (2011) extends this and describes in very clear detail the nature and purpose of such method in hermeneutic phenomenological research projects.

'Hermeneutic phenomenologists seek methods that allow the concrete, mooded, sensed, imaginative, aesthetic, embodied and relational nature of experience to be revealed.' (Finlay, 2011 p. 111)

I found this list as demanding and as daunting as van Manen's researcher credentials above but equally challenging and exciting. I had come to hope that my thesis might not only reveal these in participants' experiences, but that I could approach the whole project in a mooded, sensed, imaginative, aesthetic, embodied and relational way. While I needed to consider whether each of the above was breathing through my method, I also had the sense



that I needed to experience this holistically, like a baptism into a new way of being. I came to understand this better for myself by considering acting as something of a comparison. An actor does not become the character she is representing simply by putting on her costume. Instead to become a really convincing character, she must of course put on the appropriate clothing, but more importantly she becomes that character by her research and through immersion into the person's life. The new character can then be played effortlessly and authentically. The actor has become the character and could even ad lib in character. By spending time reading and researching a congruent philosophy and methodology for this research and by being so immersed into this, I felt able to design this unique, appropriate research method. However, along its course there have certainly been places where I felt the need to retrace my steps and to re-orientate myself, but fortunately, like Heidegger, always with renewed hope of finding my way to the clearing (Heidegger, 1971/1975 p.186). These occasions have not been debilitating but neither have they been very welcome at the time; sometimes more like the feelings I imagine an explorer might have when, having taken a wrong turn, she nevertheless finds some new treasure. At other times the 'clearings' themselves have seemed rather 'wild' and not at all the 'domesticated' (Todres, 2007 p. 19) places I expected them to be, where I hoped I might relax a little in the sunlight and fresh air. I did nevertheless find them to be places of reorientation and places from which I felt able to proceed.

The rest of this chapter is an explanation and description of my path-clearing journey: the methods used in this research. I have structured this in four main sections, the first concerning the preparation for this research, the second section is focused on the data gathering process, the third expands the methods I have used for generating further layers of data, and the focus of the forth is the method for the presentation of the data which will be evident in Chapter 7.

## Part 1

### Preparation for the Research

While phenomenology promotes a sense of openness to phenomena for new understanding to be gained and from new perspectives with creative methods, van Manen (1990, 2002, 2014) Hansen (2010) and Finlay (2011) champion the use of the word wonder to encapsulate this notion. Because I have incorporated this as an essential component of this research and not wanting to lose what I see as its naïve beauty anywhere in the process, I made a conscious plea to myself to hold onto this before I began to craft its methods. To ensure this, I pinned a note above my desk with the word *wonder* on it, with the intention of checking regularly that I maintained the sense of 'being swept up in a spell of wonder' (van Manen, 2014 p. 26). Part of my reason for doing this was because I was aware that I could not completely bracket off what 'was rooted in a metaphorical vision of (my) subject matter' the design of my methods revealing, to an extent, what I already imagined about my subject (Romanyshyn, 2013 p. 211) and the research questions I wanted to answer. Working with this tension demanded that I trusted the process and believed that I had sufficient of the qualities highlighted by van Manen (van Manen, 1990 p. 34) and in sufficient quantities. I also balanced this with Crotty's encouragement that, while with such research there is no prescribed method, researchers can 'knock' 'glean', 'learn' and 'engage' with other thinkers (Crotty, 1998 p. 216). By doing this I felt that I lessened the darkness and the isolation of the journey.

### The Research Questions and an Emergent Methods

The next step for me was, in fact, to take a step back and review my research questions. I needed to craft methods which could reveal how nurses experienced their person-centred dementia care work, and which could then lead to the discovery of the essences and the meanings of it. From this I wanted to consider how such an enhanced understanding could be used to make a positive contribution to such care in Jersey.

One of the first decisions I needed to make was how I would gather examples of lived experiences. I therefore needed to decide very early on whether or not this would include observation as this would impact upon every other aspect of the fieldwork and the way I would generate the data. Because of the complexities of this, including the practical arrangements of timing, of positioning myself discretely in busy care environments and of working with added layers of complexity associated with my interpretations of the situations I would be observing, I relatively quickly decided to focus only on the participants' spoken accounts of their lived experiences. This also meant that I would not have to work through what would have been the much more complicated ethical considerations of observing people with dementia while observing nurses at work. This however did not altogether deal with the situation. My professional work takes me into care homes and hospital wards where I find I cannot but have my eyes, ears and heart open. Inevitably what I experience in this becomes an interpretation, which I store, and which then informs my opinions. Two solutions initially presented themselves to me in response to this, the first was to extract myself from such work for the course of this research and the second was to acknowledge this and to work reflexively with what might come from it. As it was impossible to set a time frame on the data collection process and because I also came to realise that I already carried a weight of historical observations already in-forming me, the first option was impossible which meant the second became necessary. This meant that I had a further layer of reflection and reflexivity to engage with throughout the data gathering and analysis process, which I also saw as something of a benefit, because while I was not part of any clinical team, I was, quite literally, in the midst of my research field. Keeping field notes of my experiences from this early stage helped later as I worked reflexively with the participants' transcripts in the data analysis.

### Participant Interviews

Early in this research process it had become clear to me that EHP fitted well with my epistemological position and that this therefore would become my research methodology. I was drawn to its focus on embodied-being, and its

honouring of the relational nature of research, often using recorded, transcribed, semi-structured interviews, producing texts to be used for analysis following the interviews. I knew from my counselling work that empathic, non judgemental presence, the promotion of an equal power base, time, and a real interest in others' lives (Rogers, 1980/1995; Kirschenbaum and Henderson, 1990) could give people freedom to share at immense depth and that this could therefore lead to rich descriptions of participants' experiences of person-centred care. Because of the potential depth to this work and because EHP does not require a representative range (Finlay, 2011 p. 191) or attention to recurring themes or patterns, but aims rather to find what is unique in a lived experience (van Manen, 2014 p. 352-353) I was aware that there would not be as many participants involved as there could be with other methods.

### Recruiting Participants

How I would recruit the participants in a way that would encourage people from various working contexts to take part had to be considered. I was sure there were many who would agree to take part if I approached them personally, but considered that by so doing there could be an element of coercion or of doing me a favour, neither of which I wanted and neither did I want others to feel any guilt if they declined to take part. My first course of action therefore was to arrange meetings with care home and ward managers to gain their permission to place recruitment literature on staff notice boards. During these meetings I showed them both the notices I wished to display and the other supporting literature (Appendix D) including the letter of ethical approval from the university (Appendix F). This literature made it clear that staff would not be required to inform their managers of their participation and should contact me directly. Without exception, all were happy to permit this. I also planned to make use of an intranet system accessible to employees of the States of Jersey (SoJ) and to make use of the local media, but this proved unnecessary as the initial notices generated sufficient interest.

The ease with which I was able to recruit participants was encouraging and probably related to the size of Jersey, and that I may have been known through my work with Jersey Alzheimer's Association, which is a generally respected local charity. The fact that I was not a colleague of any of the participants, that I was not a HCP, but an allied professional, and that neither was I an employee of the SoJ, meant there was a healthy detachment, though close connection to the participants' person-centred dementia care. There was therefore no sense of the participants being researched by a colleague, employer or manager, or for managers to feel in any way under scrutiny, a limiting factor experienced by other counsellors and psychotherapists undertaking research (Goldman, 2015 p. 22-24).

So, with some sense of both encouragement and uncertainty I was ready to begin gathering data. At this point however, I had little idea of the length of time this would take or if the participants would feel able to contribute at the depth I needed, or if indeed I could swim down with them to such depths, while holding my breath. In my professional work I do work at relational depth but such relationships have time to develop and I learn about my clients' situations over time. I know they are motivated by the hope of positive outcomes and by the therapeutic nature of the relationship that develops and sustains them. While I was beginning to be aware of the commonalities between my counselling work and some qualitative research, I could also appreciate that boundaries needed to be put in place that would set me apart as a researcher. This essential building work seemed complicated so my final preparation was to re-view both the ethics paperwork and the British Association for Counselling and Psychotherapy's Ethical Guidelines for Research (BACP, 2004). I also reminded myself that in this context I would not be a counsellor and therefore sourced other counselling options to which I could signpost participants should any have felt the need to discuss issues raised during the interviews, beyond the scope and purpose of the interviews (Risk Assessment in Appendix D).

Soon after I began recruiting, potential participants began contacting me, either by phone or email. If they confirmed they met the criteria of being over the age of eighteen and were nurses working with people with dementia using person-centred care, I made arrangements for the interviews, which took place in either their own homes, my private office, or in a room I had made available in one of the hospitals. These interviews lasted between 1½ and 2¼ hours. Because of the need to be open to an emergent method without a pre-determined number of participants in mind (Finlay, 2011; van Manen, 2014) and being encouraged by the depth of insight from even a single case study (Todres and Galvin, 2006; Stephen et al., 2011) I did not intentionally limit this to the eight I have included. Instead, also guided by others' phenomenological research using between five to ten participants (Dewing, 2007; Byers and France, 2008; Heggstad et al., 2013) I planned to continue interviewing until I felt I had enough transcribed texts, holding a wealth of interesting, diverse, experiential data. Interviews began in May 2014 and this point was reached in April 2015. I then removed the recruiting literature.

### Ethical Considerations

Once I had decided upon the methods I expected to be using, but before any contact with the participants, I considered how I could make this ethically robust and prepared documents to be submitted for ethical approval.

In my professional work I am very used to ensuring personal information is carefully managed and that confidentiality is respected. In this research a further level of anonymity of data was essential because of the ultimate public nature of this thesis and subsequent publications, unlike my client notes which would only ever be shared in the most exceptional situations (McLeod, 2003 p. 172). For this reason I welcomed the challenge of seeking ethical approval from a university's research ethics committee because it encouraged me to plan this research meticulously, including all the

supporting paperwork that would be available to the participants (Appendices D-F). Ethical approval was granted by, The Faculty of Health and Social Care Research Ethics Committee of Canterbury Christ Church University on 24th February 2014. Prior to this, although this research is independent of the SoJ, I nevertheless considered it appropriate to approach the Minister for Health and the Service Director for Older People Services with my research proposal. Both welcomed the research and provided written confirmation (Appendix E) and once I had received written confirmation from the university's ethics committee (Appendix F) I began recruiting the participants.

Because it was necessary for participants to sign consent forms I was aware of their names, but from this stage onwards, these consent forms have been stored separately from all other documentation. Further to this, participants were then asked to choose an alternative name by which they would like to be known and it is these names only which appear on all transcripts and which are included in this thesis.

Because of the small number of participants and because Jersey is such a small island where people tend to know each other well, particularly within working environments, it became obvious that I would have to further anonymise data by the exclusive use of female names for all the participants. Very few men work with people with dementia in Jersey so I felt there was some risk that these could be identified firstly through male names and then from their roles. I had not initially planned this because I felt gender could potentially reveal interesting differences, but this became something I believed was necessary. All participants therefore have female names but include both men and women. I discussed this with the men concerned who saw the advantages of such anonymising and I suggested alternative names for them, which they found acceptable. It is interesting to note that others researching in small island communities have also implemented further layers of anonymity for similar reasons (Petrova et al., 2014).

I also considered it necessary, rather than including mis-information (Finlay, 2011 p. 191) about participants' qualifications and the length of time they had been working with people with dementia, I decided to generalise these. So, for instance, I have not specified participants' qualifications and have used such terms as 'recently appointed' or 'working in this field for some time' to indicate the length of time participants' had been working with people with dementia. For the same reason I have not referred directly to people's job titles but I have used the term 'management position' for those with responsibility for other staff. Further to this I also believed I should not specify people's places of work, nationality, ethnicity or age, but have generalised ages referring to people as 'younger' or 'mature'. And finally, although some participants did say quite clearly that they were not concerned that I anonymised their data, I have nevertheless done so. I believed that this was important because if they were recognisable in the data this would limit the field for others and potentially make them more recognisable.



## Part 2

### Data Gathering

In this section my focus is on the interview experience in which the initial data was gathered and in which some immediate layers of reflection and reflexivity most certainly occurred. Further layers of data were generated from the analysis of this data, which I have described in more detail in the subsequent section of this chapter.

I struggled initially to choose a suitable term for the processes described in this section because the idea of data 'collection', the prevalent term in most literature, and which was in some instances used interchangeably with 'gathering', (McLeod, 2003 p. 32) did not seem appropriate. This suggested something more technical to me than I had in mind for these relational, embodied, face-to-face, I-Thou meetings (Buber, 1937/1953; Merleau-Ponty, 1945/1962). Further, I could not imagine that the participants thought that the purpose of the interviews was to collect something from them, but rather more like them offering something to me. I also dismissed Finlay's suggestion of the term 'generating' (Finlay, 2011 p. 197) for this stage of the process, feeling it to be too immediate and a little too powerful, but I have however substituted 'data analysis' with 'generation' in some places in the following section. So, instead I chose the term 'gathering' which seemed to me to capture something of the organic nature of the process and seemed less restrictive, and more of a 'gathering-up-into', as a mother might gather her children up into her arms so as to hear and see and feel and understand them more nearly.

### Questions I Had to Ask

In the early stages I also wrestled with the idea of techniques and tools within this gathering process. Should I record the interview or could such recording perhaps even limit what was said as a third person in the room, an 'intruder' (Beuthin, 2014 p. 128) listening in? Should I prove myself to be the very

dedicated researcher and arrange second or even third interviews, even if I believed there to be no real benefit from these? What locations would be the best for the interviews, to enable me to gather the most useful data? Should I impose time limits on the interviews? Should I use my list of prompt questions unerringly in each interview to gather in as much relevant data as possible? Should I allow the participants to wander off my purpose for the interviews into their own subjects, the 'teller of the story' (Ibid. p. 128) leading the way? Should I assume a lead role for the purpose of putting them at ease? How much of a battle should I allow within the interview between myself as 'a knowing insider and a not knowing outsider' (Ibid. p. 129)?

### Working With My Position As An Outsider

This last question assailed me for some time with fleeting moments when I felt troubled because I was not a nurse and would therefore be in others' territories. I worried that I may not be tuned to the subtleties of the 'language' with which the participants spoke and might therefore be deafened to the whispers and songs of their lived experiences. This internal dialogue however was balanced with justifications including the familiarity of the participants' work places to me because I visit these so frequently, and of my personal experience of person-centred counselling. Accepting that even as an 'insider' I would only ever get close to another's experience through the 'teller's retelling', (Beuthin, 2014 p. 129) that I could never 'know' another's experience, and that my naivety could facilitate more openness also formed part of this 'dancing' dialogue. Then, remembering the ease with which most of my counselling clients share with me, and being reminded that story telling is a 'human art form and not a mere set of natural and spontaneous techniques to be applied' (Ibid. p. 132) and that these will arise naturally because in essence we are all 'story makers and storytellers' (Galvin and Todres, 2013 p. 15) helped me accept my position as a bona fide outsider. Later on, as each interview progressed and each story unfolded I did become more relaxed, began to feel at 'home', and aware that each participant

engaged with me in their own unique way with very little direction necessary from me.

### First Contacts

This idea of people being storied story-tellers, and very likely to have a story they wanted to tell, did give me some confidence when meeting the participants for the first time. In the first minutes of our meeting I took time to explain the purpose of the interviews again and before asking the participants if they were happy to sign consent forms I made it clear that they were not in any way obliged to tell me anything they did not want to, but that should they disclose anything that I considered potentially harmful to anyone, I would disclose this to the relevant authorities. All participants agreed to this and signed consent forms.

From this point the stance I took as I approached each interview was of simply taking time to sit with each person and asking them to share some of their story with me (Mast, 2014 p. 167) beginning each interview quite simply by asking “So, what is person-centred care like for you?” with other prompts used only sparingly and in response to what they chose to share. These included saying for example, “Could you tell me about more about that experience and how it felt for you?” or “Tell me about another time when...” This allowed me the freedom to ‘wonderingly’ inquire into (van Manen, 2014 p. 39) their experiences and then to follow the curiosity stirred up in me (Ibid. p. 33). I did not attempt the theoretical, Husserlian process of bracketing, (Ibid. p. 215) like Gadamer (1975/2013) considering this to be impossible in practice, but I did attempt what Madjar and Walton described as ‘adopting an open, ‘unknowing’ stance’ (Madjar and Walton, 1999 p. 9) with Finlay and Evans’ empathic openness and embodied presence (Finlay and Evans, 2009 pp. 93-94) to feel and respond as much as possible. In the earlier minutes of each interview I was aware of almost having to force myself into this but, when each interview had finished, without exception, I became very aware of having been in another place altogether. I felt in a sense transported, almost

deceived or drugged, because in each instance I did not know quite how I had made the journey. These felt like remarkable encountering experiences of ‘reciprocal insertion and intertwining’ (Merleau-Ponty, 1964/1968 p. 138).

These interviews certainly went beyond the “Hello how are you?” or one word answers to questions. Like Beuthin I found them to be times of peace and privilege (Beuthin, 2014 p. 130) and of listening not only to the words spoken but also of ‘listening to the worlds’ the participants inhabited (Williams, 2005 p. 27). This took time though because in most cases, although all participants clearly wanted to talk with me, they initially seemed to want to tell me what they knew *about* person-centred care and to *explain* it to me, reflecting perhaps what Benjamin says that ‘nowadays no event comes to us without already being shot through with explanations’ (Benjamin, 2002 in Frank, 1995/2013 p. 191). It was mostly only when I emphasised the word *experience* quite deliberately and said that I did not want to presume that I knew about this because I knew the *theory* of person-centred care, that the nature of the sharing changed to a more obvious focus on their experience as it was for them. These ‘direct descriptions’ from experiences of the lifeworld (Merleau-Ponty, 1945/1962 p. vii) were exactly what I wanted so after the first few interviews I introduced this emphasis almost immediately.

When I reflected on this willingness, almost a need, to share some seemed to be expressing, the song *Soul to Soul* by the Temptations came to mind again. These words just seemed to sum this up.

‘Like a notebook... on a shelf  
Tired of talking to myself  
Wishing somebody passing by  
Would pick me up and look inside....  
All I want is a friend I can talk to soul to soul.’ (Motown Records, 1989)

Listening to this song, I felt that the interviews had offered a ‘soulful space’ with the mix of vulnerability, space and freedom that Todres (2007 p. 162) says comes with letting go and opening up, which seemed true both for myself and for the participants. I am convinced that this was facilitated by the

fact that I had considered the tension between needing data and providing a soulful space and had opted to,

‘listen with the totality of (my) being and the entirety of (my) personality’ (Colaizzi, 1978 in Balls, 2009 p. 4)

to what might be offered. Inevitably this did mean that some of the data did not seem relevant and some interviews had more of the feel of counselling sessions for a while, but as Cooper described, (Collins and Cooper, 2014 p. 97) choosing a mode of empathic listening always allowed space and an eventual return to the research subject.

### Embodied Presence and Body Talk

It was most certainly the case that the choice and intonation of the words and their pace and structure in sentences used by me and the participants, affected the descriptions I was gathering and their ability to point to essences and meanings. However I was also aware that the words themselves were not saying all there was to be said. It was clear to me that as much was being said by the silences between the words and by the two bodies in the room as with the words themselves. Our bodies seemed to be actively engaged in their semaphore language and having their say. I had dismissed the idea of filming the interviews because of the camera possibly being an intruder too many, but it did occur to me that this could have brought further insight. Memory, and the marvellous ability of the body to churn up words, pictures and emotions instead had to do the work of the camera.

Gendlin’s (1978/2003) ideas of the implicit made explicit through the ‘body which speaks’ was not new to me as I use his *Focussing* in some of my counselling practice, and while focussing is not intended as a study of body language, something of this related idea is probably known by us all and I think described beautiful in Ronan Keating’s song *When You say Nothing At All*.

‘It’s amazing how you can speak right to my heart,  
Without saying a word you can light up the dark.

Try as I may, I could never explain  
What I hear when you don't say a thing.  
It's the smile on your face...  
Truth in your eyes...  
The touch of your hand... (Ronan Keating, 1999)

My experience of *Focussing* in counselling practice not only helped focus my attention on the participants' body language in the interviews but was also helpful as I dwelt with the data after each interview to generate further insights. However, I found Merleau-Ponty's ideas of embodied being even more helpful for this time of data gathering. This was because it is not so much of an applied technique but an essential reality of being. From this I have come to understand that although words are spoken from, and through, and with our bodies, they are also in a way held up as they are being constructed in the mind. This makes them perhaps more of a construction whereas the speaking body before, or instead of words, seems perhaps more original and more naïve and perhaps more honest. This also resonated with Galvin and Todres' ideas of 'an embodied contemplative approach' which I welcomed with its 'slowing down, in-breath' (Galvin and Todres, 2013 pp. 145-146). Although of course a mystery will always remain as neither a body nor words can say it all, I did 'record' as much of the embodied experiences for later reflection as I could. Frank summarises this well writing,

'The body is not mute, but it is inarticulate; it does not use speech, yet begets it' (Frank, 1995/2013 p. 27).

As I reflected on this and recalled the range of my own body's responses throughout the research process the following poem began to emerge, which I have called *Body Words*.

#### Body Words

I guess *it's* that indescribable thing  
Because there are just no words,  
So *it* stays in my body.  
I'm dumb,  
Shocked into feelings alone,  
Sometimes burning my soul and othertimes  
Inflating my anger till I feel I'm flying above

And looking down from a somewhere else,  
Or warming my heart till I'm bubbling up,  
Or *it* chills me to the bone  
So I feel I'm ready to snap,  
Or shivers my skin  
Till the goose-bumps appear,  
Or crashes into my mind  
And buggers up my brain  
Till there is no thinking space  
Remaining – *it's* throb leading to real pain.  
And then to my eyes,  
Can the tears say *it* all  
With their wordless work?  
And the deep breath in,  
Is this where  
New words are born?

### Active Listening

Active listening, the time, space and welcome given to another's communication by words and the language of the body, was an essential part of the data gathering process. Prior to this however, I had not noticed the extent to which what is spoken is always in direct relation to that which is said and of the implications of this. During the interviews it became clear that Merleau-Ponty was quite right when he wrote that 'Speaking is not just my own initiative' and 'listening is not submitting to the initiative of the other' (Merleau-Ponty, 1973 p. 144) because my next words were already being formed as I listened and were crowding into the listening space. In this I experienced some tension but also as I loitered 'in the presence of what (was) present' (Romanyshyn, 2013 p. 232) I was aware of a deep, relational flesh and world intertwining and a sense of being a co-creating dialogical partners, through a symbiotic fusion of horizons (Gadamer, 1960/2013 pp. 382-383).

This was my experience throughout the interviewing process with perhaps some increased confidence in each and with a feeling of being more at home and comfortable with what I was doing. Because of this I felt able to hold onto more of the unsaid in the room and was able to be more present and more

empathic in my being-with the participants. When I eventually pressed the stop button on my recorder for the last time I was confident that what that small machine held within it and what I held in my body was a living resource for further data generation.



## Part 3

### Dwelling with the Data to Generate Further Insight

This section describes the methods I used immediately following the completion of the interviews to beginning the written presentations of the research findings. Although this seems quite linear, it was often not so as I found myself returning again and again to the transcripts and through these back to my lived experience of the interviews and my meeting with the participants. Sometimes this felt like I was swimming up-stream and seemingly getting nowhere and then being swamped by a massive tidal wave of new insight. It didn't always feel good and at times I questioned if I would ever get to the final full stop. But I learnt to stay with these feelings and eventually I did begin to see them as welcome intruders bearing gifts. Alongside these feelings I also become increasingly aware that, even as I greeted each participant, interpretations were already forming, which then became more lively as I reflected on each interview and began to transcribe them. This sense of something growing in me was rather like being pregnant, the 'child' although immature and naïve, was becoming more animated and responsive, already able to speak with sophisticated language. At this point it was helpful to remember that at birth we cannot know the adult in the child and that it is only time that will can reveal this. I was thus encouraged to restrain the temptation to come to any final analysis too soon.

### Transcribing

I had chosen not to use any of the transcribing tools like NVivo or TranscribeMe or to engage others to assist in this process because I wanted to keep myself attached to the texts and to allow them an opportunity to continue to speak to me throughout this process as though I was still in the room with the participants. I also believed I would be a more accurate 'tool' and that this would keep the texts alive and breathing for longer and enable me to,

'pick up on nuances, hesitations, pauses, emphases and the many other ways that people add meaning to their words.' (Etherington, 2000 p. 292)

I began this process as soon after each interview as possible, not wanting time to erase anything. It was an ordeal both physically and emotionally and when I eventually pressed the recorder's delete option, only the transcripts remained, heavy beyond their paper-thin appearance. In response to this process I wrote the following.

#### How Much Can Paper Weigh?

Each page, so paper-thin,  
Weighing nothing, weighs a ton  
So loaded up  
With words and meanings.  
The scientist in me says this cannot be,  
So, with re-awakened curiosity,  
Scales, equations ready,  
I analyse and measure  
With numbers to explore  
The uniqueness  
Of this phenomenon,  
To find out more  
And be done.

With nothing surfacing,  
No explanation found,  
I try another scheme  
To glean the meaning of it all.  
So I wait, I breathe, I wonder and I reflect  
And stretch my reflexive self instead  
To every word and phrase.  
And with a felt sense now emerging,  
Words tumbling into their meaning,  
And seeming  
So heavy in my hands  
Say it all  
And I know.

#### Beginning to Make the Music

The transcripts then became the means by which the participants' private worlds were no longer theirs' alone and, using Merleau-Ponty's metaphor,

became 'instruments' I was playing to generate further insights (Merleau-Ponty, 1964/1968 p. 11). This was not so much action orientated, like following a manuscript, but was more extemporarily creative with 'passive receptivity' (van Manen, 2002 p. 251) determining the style to find embedded essences and meanings through their reading and re-reading. This passivity required I dwelt with these transcripts, a process in which I welcomed both the power of words and of speech to make 'meaning out of life' (Merleau-Ponty, 1973 p. 142, 146) and the body, heeding Todres' call to listen to the lived body as the 'messenger of the unsaid' (Todres, 2007 p. 5) by dipping between the felt sense and language. This was demanding and at times it sometimes seemed difficult to let go of them, being keen to explore them further.

Although I wanted to get on with this process, I first made every effort to put some space between myself and each transcript by slowing down my responses to them with the 'in-breath' prescribed by Galvin and Todres, (2013 p. 146) by so doing loosening any unintentional hold I may have had on them. This sense of offering space for each to speak for themselves was hard but when I took them up again I felt I was in a better position to listen and, with my re-membered body, (Gendlin, 1978/2003, 2014) to feel them speaking and to view them from a less limited perspective. I stayed with the full transcripts initially not looking for anything in particular but welcoming anything. This mostly did not lead to striking insights but was helpful in making me feel once again connected with the participants.

Following this, rather than using the more technical tools of coding and counting themes in the data and assessing the frequency of these as in some human science research, I chose to hold onto a sense of wonderment and what van Manen referred to as the,

'more complex and creative process of insightful invention, discovery and disclosure' (van Manen, 2014 p. 320).

So, from the 'wholistic', 'selective' and 'detailed reading' (Ibid.) I then set about considering what felt or sounded significant or intriguing. Very soon the texts were covered in pencil under-linings and annotations. My interest was heightened and especially so when I began to move between the whole texts to parts of them and from my fore-understandings to the newer emergent themes, a process Dilthey termed the 'hermeneutic circle' (Dilthey, 1900/1976; Polkinghorne, 1983 p. 227; Finlay, 2011 pp. 115-116) proposed for the purpose of stirring up deeper insight. Through this it was becoming obvious that although the language was often 'indirect and allusive' (Merleau-Ponty, 1960/1964 p. 43) there was so 'much more' than was said (Todres, 2007 p. 79). Phenomenological meanings were emerging from the texts through the continuing dialogical partnership of my interpretation of the participants' texts and creating new, emergent, sometimes only gentle whispers and other times more structured songs.

### **Incorporating Lifeworld Existentials**

With my focus on the lived experience of person-centred dementia care, I decided to follow van Manen's and Galvin and Todres' suggestions, based on Merleau-Ponty's earlier ideas (Merleau-Ponty, 1945/1962) of using lifeworld existentials to guide my reflection further. Van Manen initially proposed four existentials, temporality, spatiality, relationality and corporeality (van Manen, 1990 pp. 101-106) and then later included materiality (van Manen, 2014 pp. 302-307) all of which I included, together with Galvin and Todres' addition of mood (Galvin and Todres, 2013 p. 29). However, because Buber (1937/1953) and Lévinas (1961/1969) incorporated materiality within relationality, as people relate to things, I did consider combining materiality with relationality, but when the data seemed to be offering itself in the six categories, I dismissed this option. These existentials then became the new foreground of my focus as I looked for examples of each in the texts to help me explore essences and meaning aspects of the lifeworld.

Very quickly I began to see clear examples of these in each transcript and the earlier pencil marks became entwined with a rainbow of six colours marking out each and often over-lapping. These seemed to offer stature and structure and became the headings under which I have presented some of the data in Chapter 7. While they did not become 'thematized' objective truths (Smythe and Spence, 2012 p. 14) in themselves, I saw them as becoming a rainbow to the pot of gold of essences and meanings, and 'partner(s) in (my) journey of thinking' (Ibid.) and for creativity.

By the time I had worked through each text it was true to say that little was left uncoloured, about which I was rather pleased as I believed this validated my use of the six existentials. However there were some parts lying outside this colourful spectrum and it was to these I turned before their dismissal. Iser (1980 pp. 94-95) drew attention to the Gestalt psychological terms of 'figure' (the existentials in this case) and 'ground' (the uncoloured parts) writing that 'we always select specific items from the mass of data...a selection governed by our expectations' and that we have often 'taken no account of' the (back)ground. To help explain this process more visually he uses the example of Rubin's vase (Pind, 2014 p. 214) in which the viewer, if looking for a vase will see a vase, but if looking for two faces in profile will see these. This cautioned me to consider the colourless matter before me, which did, with more radical reflection, (Merleau-Ponty, 1945/1962; Dewing, 2011 p. 73) offer further insights I might otherwise have missed. I have drawn attention to these instances in Chapter 7.

### Radical Reflection and Reflexivity in Deep Water

In this existential hermeneutic phenomenological project the participant's descriptions of their lived experience, offered through their speech and then through the transcripts, were one of the vehicles of 'movement towards truth' the other vehicle being mine, and the participants' embodied selves for 'being in the world' (Merleau-Ponty, 1973 p. 129). With these annotated transcripts and re-membered meetings I continued to deeply immerse myself into and radically reflect upon these lived experiences and descriptions (Merleau-

Ponty, 1945/1962; Dewing, 2011 p. 73). While in this pool I endeavoured to tune into the subtle nuances of the spoken words and the felt senses of my body speaking out from its 'recesses' (Merleau-Ponty, 1964/1968 p. 9) as new interpretations began to take their hold. This was full-on with no sense of 'putting things to one side' (Dewing, 2011 p. 73) engaging, as Dewing had done, cognitively, aesthetically, reflexively and with my body's felt sense. This meant that I had to also consider how merging echoes from my past might have been seeping into the water and changing its texture, and my own very real observations of person-centred dementia care mixing in too. I had to wrestle in the water with unwelcome ideas of my judgement of others' practice, the turbulence surfacing feelings of guilt in me. Alongside this I experienced a very different sense when, remembering the feeling, almost like patting some of the participants on the back for their (in my opinion) good practice, I got a sense of the pool drying out, of being left high-and-dry with nothing. On these occasions I knew I had to re-orientate myself to the irrigating waters of a more 'original, creative singing' (Merleau-Ponty, 1945/1962) rather than running with my own limited perspective. This idea is also contained within my earlier reference to Aslan's singing as he beautifully and evocatively, quite literally, sings creation into being (Lewis, 1955/1998 pp. 114-133). This was not however the interpretation of some other characters who's judgments were of a dangerous, roaring, wild lion. Their own pre-understandings dried up any access to the beauty of the 'original singing' that the others could see. I am sure that Lewis must have been inspired by Merleau-Ponty as he wrote this, and I took heed of its warning.

At the start of each interview, and again at the end of each, I offered the participants the opportunity to review the transcriptions of their interviews to check the content was accurate and to draw my attention to any details they wanted deleted. Only one participant, someone who had seemed slightly more anxious than the others about the content of the interview prior to this taking place, wished to see their transcript, but on its receipt, immediately accepted it as accurate and required nothing to be changed. This was good

affirmation, which gave me confidence I had transcribed them accurately and soon to reveal their wealth of data. So, with all the completed transcripts I began the next stage of analysis, which forms the content of the next section below.

## Part 4

### Crafting and Writing to Present the Data

In this section I describe my crafting and then presentation of the data in Chapter 7 by continuing to dwell with it, to reflect upon it, work with it reflexively, allowing my body to have its say, and interpret it, thus achieving its co-re-created poetic content letting, 'poetry works its magic' (Touchstone, 1989) and words become 'image' (van Manen, 2014 p. 261). While it is true that this content could not have come about without moments of inceptual insight (van Manen, 2014 p. 237-238) along the way, it is also true that I set about purposefully crafting each word, phrase and sentence with the intention and hope of 'awakening a spark' (Galvin and Todres, 2012 p. 130) of interest in the phenomenon which has engulfed me for so long and that this might illuminate the pathway for new interest to grow into a 'more deeply understood worldly engagement' (van Manen, 1990 p. 129).

To help develop these ideas further, I have included Galvin and Todres' beautifully crafted poem *Writing Up* (Galvin and Todres, 2009b pp. 312-313 Appendix G) because I believe it encapsulates so much of my intention and experience in this process.

### Focussing on the Participants

Rather than reviewing all the data together or with each existential in turn (as Rich et al., 2013) I worked with each participant's data separately before moving on to the next. I felt that by doing this I could retain more of the existential nature of this project, allowing each participant a clearer voice, uncontaminated by the others' singing. Therefore in the first stage of this process I returned to each transcript as a whole, following this with a more detailed focus on the six existentials in turn. Where I felt particularly addressed by what I was reading I paused, allowing my body to be the 'messenger of the unsaid' (Finlay, 2013 p. 256) and encouraging words to emerge from my 'felt sense' (Gendlin, 1978/2003) feelings. I then set about working with these poetically, welcoming metaphors as they slipped into my



mind, to add layers of interpretation for the purpose of pointing towards what I was seeing and feeling and hearing. At other times I chose to present quotes from the transcripts using an extended written form that Vanier (1988) Schuster (2013) and Tuama (2013) have used to great effect and which I believe helps to communicate the pace, emphases and mood that I felt. In addition to this I also made use of spacing, bold type and alternative punctuation, beyond more conventional prose, to help communicate further the timing and emphases I heard and felt in the participants' voices and bodies.

At the end of this process I believed I was nearer the experience of person-centred dementia care for each participant and therefore completed each section with tentative suggestions for the essence and meaning of person-centred dementia care for each participant. Each of these sections then became the participants' individual portraits.

### **Focussing on the Existentials**

I followed this with a shift in focus from the participants' portraits to the six existentials. I was aware that this could be risky and felt the tension of wanting to 'retain the richness and texture of individual experiences' (Todres, 2007 p. 7) of 'staying close' (Ibid. p. 8) to individual uniqueness and of wanting at the same time to consider the 'social and perhaps universal significance' (Ibid.) of these experiences. I tasked myself with holding onto both.

In this stage I spent time reflecting upon the sections in each participant's new data attributed to each existential, for the purpose of creating space specifically for embodiment, spatiality, temporality, mood, relationality and materiality to emerge, combine and intertwine from each participant. These merged meeting places were mostly busy and raucous, but also strangely harmonious events, as I listened and listened again, re-lived, radically reflected upon, opened my eyes wide to see, tuning my ears to pick up the

subtleties and senses of it all. It took me over so much at times that I believe I was inseparable from it and was sure I often carried all this into my dreams and other parts of my life. Gendlin wrote that it is 'our bodies that do our living' (Gendlin, 1992 p. 2) and I was aware of feeling both enthralled by the process and also distanced from others around me for whom this world was inaccessible. I spent some time working with these feelings, often experimenting poetically with them, and once named they did seem to be less invasive. I also found some peace in this from the idea that colleagues and family who had sensed my distance would be able, through the finished thesis, to come closer to phenomenon that had distracted me for so long.

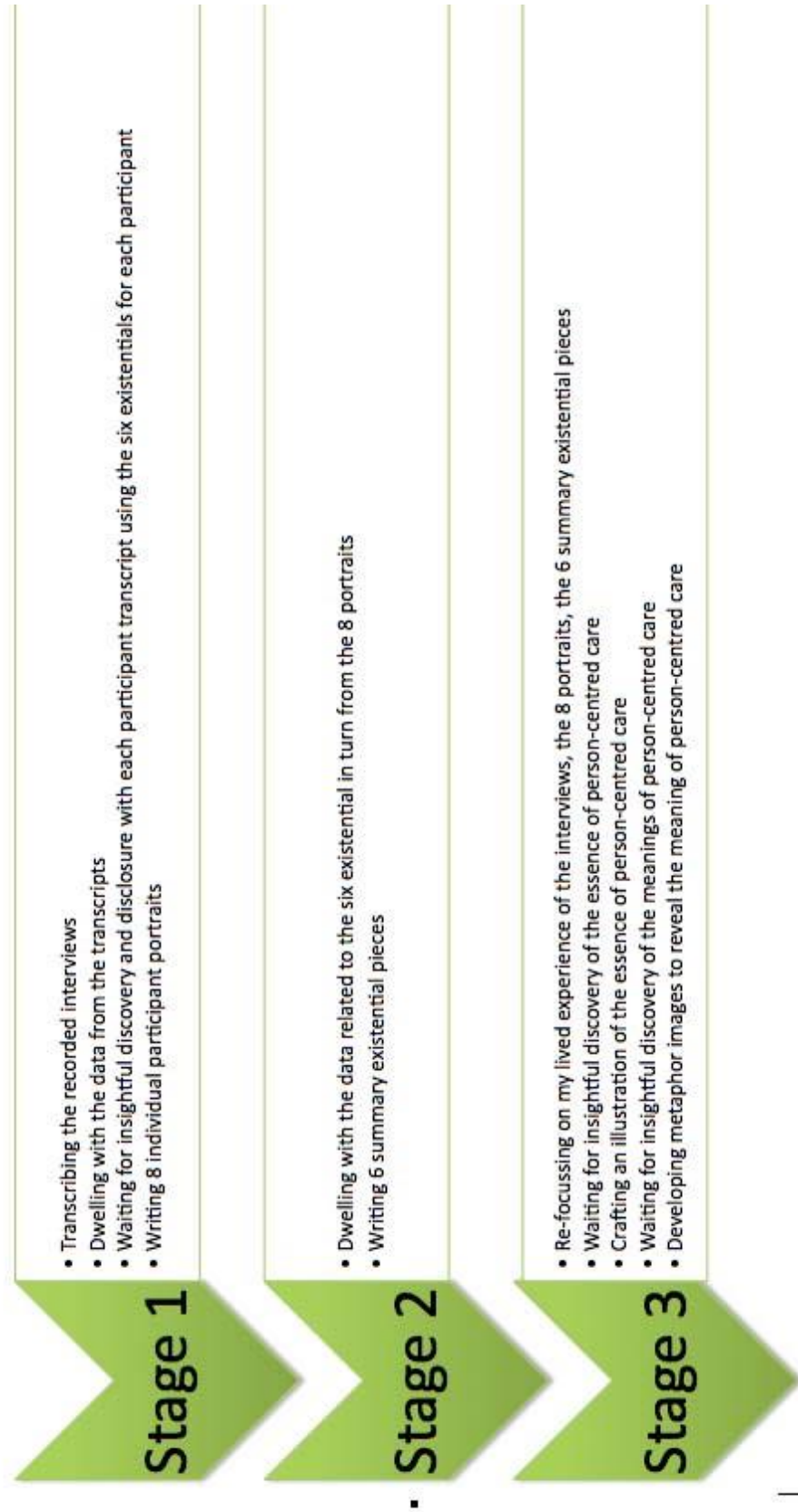
Spurred on by this and reminded that what I was attempting was not the 'mechanical procedure' (van Manen, 1990 p. 96) that I was imagining, but rather a linguistic, creative, artistic endeavour from a 'reflective mood' (Ibid.) offering 'open space' (Gadamer, 1986 p. 27) for the reader to fill, I began to write freely and with more confidence. Working through the data from the eight participants for each of the six existentials was however a massive task, not only because of the sheer amount of data but because I was continually being struck by its poignancy, both of the unique and the emergent shared experiences. I kept going until I had six summary pieces for each existential, and as with the initial data and portraits from the individual participants, this sometimes incorporated the 'short step' to poetry via embodied interpretation (Galvin and Todres, 2009 p. 308) and also the use of metaphors as they arose. Unlike Rich et al. (2013) I did not consider it important to present these in any particular order, allowing instead the data to draw attention to itself and 'whisper or sing' of its own relative importance for the reader.

### **Towards Summary Essences and Meanings**

A third stage followed this in which I used the eight participants' data and the six summary existentials to develop summary essences and meanings of person-centred dementia care for these participants working in Jersey. To

achieve this 'Pulling it Together' (Finlay, 2011 p. 248) I certainly needed to engage Finlay's tactics of 'stepping back' and selectivity (Ibid. p. 249). My first task after this stepping back was to first seek the summary essences which I arrived at from my direct contact with all the words around me, keeping hold of those which seemed more 'universal' (Heidegger, 1971/1975 p. 189). My search for summary meanings followed which I found were 'not so much in the words as in the palpable presence of something' (Galvin and Todres, 2012 p. 129) that I knew to be true and real and there with me, which involved my interpretative working with all the data including the summary essences, these stages being summarised in Diagram 3. This process, unlike some research using deductive reasoning to reach logical or true conclusions, or inductive analyses to make broad generalisations from specific observation, is more preductive and abductive (van Manen, 2014 pp. 344-345) which van Manen described by using the term 'aletheia' (Ibid. p. 342) to represent the qualities of 'disclosure', 'unconcealment' and 'openness' associated with these terms. My analysis began with the preductive, active passivity I have described above, facilitating the creativity for interpreting essences and meanings from the data which have then abductivity led to the outcomes from the data I have presented in Chapter 8.

Diagram 3: Stages of Data Analysis



## Reflections on this Experience

This task was much bigger than I had ever imagined it could be and to persevere I needed to believe there was purpose in my endeavour beyond knowing that 'my heart (was) in tune with the spirit and nature of the work' (Romanyshyn, 2013 p. 17). At times I literally clung onto van Manen's, Todres' and Finlay's words for encouragement, heavily marking their books and papers and covering my study with their significant wisdom. So often phenomenology, and particularly EHP, appeared to me to go against the grain of other academic writing so I relied on them for this encouragement and guidance. I needed to be reminded that I did not need to present truths by the clever use of evidence and logical theory. My task was to bring myself, and my readers closer to the phenomenon to feel it, touch it and know it better. Like Buber I wanted to make it my only wish 'that I might heighten this reality' with 'true art' 'true science' and 'true philosophy' (Buber, 1957/1974 p. 28). Sometimes I did feel overshadowed with concern about the choices I was making, my limited giftedness in writing, (Finlay, 2011 p. 255) that my tentative blending of poetry with the texts could bring down the mist on new understanding, and once detached from me my words could lose what meaning they ever held. But there were good times too, when I knew the words I had chosen had the potential to illuminate and reverberate and break into new understanding, this mysterious process so beautifully summed up by van Manen.

'It is in this writerly space where there reigns the ultimate incomprehensibility of things, the unfathomable infiniteness of their being, the uncanny rumble of existence itself.'  
(van Manen, 2002 p. 243)

## Summary of the Method

This research project began with wonder, which led onto questioning, and then the construction of this research method. Interviews were carried out and the transcripts from these were analysed in depth, interpreted and written up, incorporating poetry and metaphor to present participants' lived

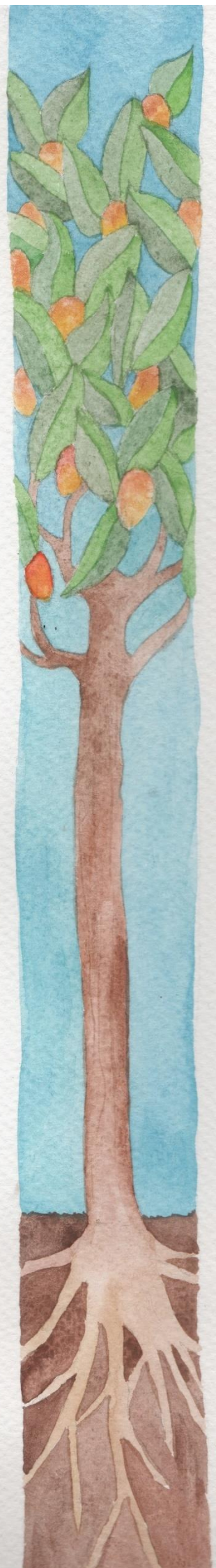
experiences and the essences and meanings of their person-centred dementia care. It has been an opportunity to wonder and wander beyond facts into mystery, from shadowy paths to brighter clearings with radical reflection to balance tensions and to assist in remaining open to the yet to be known. It has required me to engage with the meaning of being an embodied, relational human, as I have looked for ways of capturing and representing those aspects of experience that participants have voiced, together with those which were more implicit. Therefore, this open, creative, sometimes 'erring' research method proceeds,

'on the basis of an epistemology where understanding is never simply cognitive, but is always intertwined with senses, moods, qualities and multiple inter-subjective and cultural contexts.'  
(Galvin and Todres, 2012)

I believe it is personally congruent and an appropriate means for answering my research questions. It is a new path and has been a productive way towards a new human understanding of person-centred dementia care. The following chapter is now dedicated to the data analysis as described above.

## Chapter 7

### Whispers and Song: Presenting the Data



## Chapter Seven: Presenting the Data

### Whispers and Song

‘For forty-eight hours I’ve done nothing but type. I am stupid with facts about other people’s lives. My eyes sting with the smell of typing ink. My fingers are striped with paper cuts. Who knew paper and ink could be so vicious.’ (Stockett, 2010 p. 357).

In my introduction to this thesis I made reference to the book *The Help*. This quote is from that book, which I have included here, not because I can identify with the smell of typing ink (even I have moved on a bit beyond that) nor do I have any of the writer’s paper cuts to show for my labours, but I do share something of the deeper meaning I can hear in and between these lines. I am full up with stories, my head is buzzing with facts, with detail, and many, many words mixed in such a storied array of action and drama, my heart is turning over and over, and yes, I am tired after hours of typing and my wrists really ache. But there is also passion and motivation in these lines, powering Miss Phelan to keep going. I feel this too.

### Introduction to the Data Analysis

‘Phenomenology, not unlike poetry, is a poetizing project; it tries an incantative, evocative speaking, a primal telling, wherein we aim to involve the voice in an original singing of the world.’ (Merleau-Ponty, 1973 in van Manen, 1990 p. 13).

The purpose of this chapter is threefold, firstly to discover the lived experiences of person-centred dementia care for nurses in Jersey, secondly from these to come to an understanding of the essence of person-centred care and then finally beyond this to discover, through my hermeneutic working with the data, the meanings of person-centred care for nurses in Jersey. Because I have listened to the participants’ stories so many times, I now have a sense of being fully immersed in, of being baptized into, the lives of the participants. This data has been formed from the earth of its philosophical grounding and has been chiselled into its shape by the



methodology and the methods I have developed throughout its process. My intention, following Merleau-Ponty and van Manen, has been to encourage you to hear something of an 'original singing', to present to you the chance of hearing a 'new voice' on the subject of person-centred dementia care, which is not exclusively your own, or the one you may know well, and which may be very unfamiliar to you. It is my intention to help you leave behind what you already know, and in a sense 'un-name' this (Madjar and Walton, 1999 p. 19) and tune your ears to a new sound echoing in the following lines. It is not just about you reading this script, and perhaps nodding in agreement or recognition, but it is about 'thinking on original experience' and in a,

'language that authentically speaks the world rather than abstractly speaking *of* it' (van Manen, 1990 p. 13).

This chapter is divided into three sections, focussing firstly on the participants, secondly the existentials and finally on the summary essences and meanings of person-centred dementia care, through which it is my hope that you will find newness in, or through, or even '*in spite of*' (Ibid.) these words, 'spoken' by me, and the participants' inter-harmonized, fused voices and that you will have some sense of knowing and relating to the participants through their lived experiences of person-centred dementia care.

### Confidentiality and Anonymity of Data

I have given attention to issues related to confidentiality and anonymity in Chapter 6 so here I need only to remind you that the participants' names have been changed, as have the names of the places they work and that all participants were given female names to disguise gender. I have also changed or redacted some sections that could have made participants more recognisable and have not included complete transcripts or lengthy sections of these in the appendix for the same reason. The sections I have included in this chapter have been selected with care and with participant confidentiality and anonymity paramount.

## Descriptions, Lifeworld Existentials, Poetry, Quotations and Punctuation

As this chapter progresses you will see that I have described the interview process and have written about each participant's data in varying amounts of detail and given more, or less attention to each of the lifeworld existentials. I have also used quotes from the transcripts, poetry, metaphor, enhanced spacing and varying fonts throughout in differing amounts and places to help communicate the participants' varying emphases, tones and timing. This has been the outcome of my creative openness to the phenomenon and to what has been revealed to me through reflexive engagement, reflection and more radical reflection, following the guidelines offered for phenomenological research by van Manen (1990, 2014) Galvin and Todres (2009b, 2012) Dewing (2011) and Finlay (2011). It has therefore been something I have done 'with the data, rather than saying something about it' (Rath, 2001 p. 117) to reflexively develop meanings, and to provide density and aestheticism (Ricci, 2003 p. 590). This has been part of the adventure, creating the path along the way, with scythes in hand, off into the unknown and with highlights, tiring days, those which just seem to be mile-killing, and others bringing wonderful vistas and revelations of the new. The following pages reflect this with the sights and sounds and experiences I have had along the way.

### Stage 1: Focussing on the Participants

#### Participant 1: Jane

##### The First of all the Interviews

It was like the first day at school. There was no uniform or school bag to concern me but just as that day many years ago my body did not obey its shaky commands as accurately as I needed it to do and I felt a little panicky and rather sick. The more I reasoned the unreasonableness of this with myself, the worse it became. What seemed to trouble me most, and what I seemed to come back to again and again, with horror thumping through my

chest, was the awfulness of technology! What if the simplest of recorders would not work, flat batteries or user's error? So I tested the thing yet again. It worked. It would work again in an hour. Some minimal comfort ensued with a gentler pulse. But then I progressed on to worrying that the person I was about to see might change her mind, clam up or really have nothing to say that I needed to hear. All this was so unexpected for me. I had used the same recorder not so long ago (but not recently enough to be convinced that it really was reliable and trustworthy) and further, I knew from the nature of the work I do, that people generally do feel at ease talking with me, sometimes sharing their deepest thoughts and emotions that they may never have shared with anyone else. It was only when I actually got to the interview location that things changed. The journey there had been awful but Jane was warm, relaxed and happy almost immediately. The recorder worked and we were off. The fieldwork had begun. A momentous occasion and probably, of course, the real deeper reason for my nerves.

#### Initial Reflections During the Interview

I think the sense of calm, which exuded from Jane, helped me relax almost immediately and was, in retrospect, a lovely gift to this research. I felt so encouraged and very at home doing what I was doing. I felt like a real researcher! But as the interview progressed, I also remember a growing sense of anxiety somewhere alongside this, because I seemed to be hearing exactly what I was expecting to hear. I wondered could this be right? Could I be missing the point because it seemed to be too easy? Was I just hearing what I wanted to hear? At the time, I was aware that these thoughts seemed to override any feelings I was expecting to feel, related to what Jane was telling me of her actual experiences. When I realized this I made every effort to bring myself back into her experiences and, important though I knew they were, I tried to leave mine aside.

I was aware of this continuing sense of myself somewhere outside of Jane's world throughout the rest of the interview but I think I became more

peacefully accepting of it, perhaps because what she was saying sounded familiar, and therefore not too complicated, and in some sort of harmony with me. It was easy listening.

### Further Reflections and Engaging Reflexivity

I began to transcribe Jane's interview not long after I had completed it. This task was just as arduous as I had been warned it would be, but nevertheless my aching head was soothed by the cool breeze of finding that what I had felt sure was useful and enlightening material during the interview, was certainly emerging before my eyes as something obviously substantial. This, perhaps naively for this stage of my research, filled me with a huge sense of confidence for its progression and for subsequent interviews.

Soon after this, and during my second reading of Jane's interview transcript, I found that the smallest of smiles that had etched itself onto my face in the first reading, had developed into the broadest of smiles, now almost filling my face. In this initial reflection I heard myself saying to myself "She really gets this, she really does", words which led me to feel a deep sense of hopefulness and confidence that the care in Jane's work-place would certainly be impacted by someone as heart-full and passionate as she. This was brilliant. I also felt very familiar with the text and almost ready to move on to writing.

I stayed with these feelings for some time and loved it all. However, coming back to this a few days later I found myself to be somewhat and unexpectedly troubled, where previously for me there had only been delight for the future of this research and hopefulness for the context of Jane's work. Reflexively working it through I asked myself what I was feeling, using Gendlin's pattern for focussing on myself (Gendlin, 2003) something I occasionally use with my clients in counselling and with myself when I feel the need to dig a bit deeper, to uncover mysteries my body seems to want to reveal, or that I just need to discover. This was one of those occasions. I

knew something was wrong, and as I stayed with this sense I began to see that what I had heard myself saying in “She really gets *it*”, was hardly her voice but mine. The *it* was a type of matching, or aligning to my *it*. My experience of person-centred dementia care was blasting out hers, which I had unintentionally kept as a whisper, hardly audible at all I realised. I was so focussed on my experiences that I was sure my voice was speaking Jane’s experience with far too much dominance, rather than as the balanced fusion of her horizon with mine, the duet it should have been.

I felt pulled up by this experience but then immediately comforted myself by purposefully returning to van Manen who makes it clear that connection with the text is only possible through pre-knowledge of, and affinity with the phenomenon. Without this he says appropriation is difficult, texts remain difficult to understand and meaning is illusive, making it almost impossible to make what belongs to the other, one’s own (van Manen, 1990 pp. 46-47). Comforting words in this context - but I could see this was much harder in reality to do than I thought only a few days earlier.

### Jane’s Experiences of Person-Centred Care

Even as I listened to Jane describe her experiences of person-centred care in the interview, the lifeworld existentials of spatiality, temporality, relationality, corporeality, mood and materiality seemed to present themselves in remarkable clarity, so much so that I was confident, even at that stage, that these lenses would help me to explore Jane’s lived experiences of this phenomenon more deeply and to find the essence and meaning of person-centred care for her (van Manen, 1990 pp. 101-106 and 2014, p. 302-307; Merleau-Ponty, 1945/1962). As my immersion into the text continued however, it became more obvious that although these were useful links, or hooks into the text, they in reality over-lapped in the descriptions Jane was sharing. Although Rich et al. (2013 p. 501) suggested the existentials were not ‘sharply separable’ I had not expected the degree to which they appeared to be interwoven, so chose to draw attention to them

individually and work with them together as they seemed to require. I followed this pattern for all subsequent transcripts and analyses.

### Corporeality and Relationality

When quite literally walking away from Jane's interview transcript to spend time reflecting upon the whole interview, the description which seemed to have taken hold of me most profoundly was of the time Jane had spent with the person nearing the end of her life yet who was physically still quite actively looking for her mother or daughter for the comfort she seemed to be craving. Jane's description of this was becoming so profound, so clear and so poignant to me, I almost felt I could have been one of her colleagues standing and observing. This chilled me. I wondered where I would have been in that room? Jane talked of this lady being sedated and of her then lying on a mattress on the floor.

'I could see her **lying there**  
looking so anxious and **alone** there on the floor.  
I just had to get down there **with her** –  
to reassure her, and to tell her she was safe –  
or something like that while I waited for the medication to work.  
I lay there **hugging her** from behind, **stroking her** head and hand,  
massaging it, and her feet, telling her she was safe.  
But I could see the others there -  
who came in and were **horrified** at that -  
**I could see that** – but I remember thinking I didn't care - you know -  
I thought – if she feels safe, and I'm lying on the floor, that is fine by  
me -  
and - if **she thinks** I'm her daughter or mother, well that's ok too.'

I could see and feel this scene so well, of Jane offering this person her sympathetic presence and the physical comfort she seemed to be craving. As I immersed myself deeper into more radical reflection of the transcript, I was aware of becoming quite churned up, with a whole host of emotions taking hold of me. These seemed to deepen all the more as I began to write, and rewrite the poem *Unthinkable Comforts*. My emotions ranged from anger with myself for missing opportunities like this when I could have offered such physical comfort, my regret for being judgemental of the other staff who

considered Jane's willingness and ability to work so holistically and at such corporeal and relational depth as unthinkable, and deep sadness that such emotional pain is so real for so many with dementia and that such difficult caring dilemmas are so real for so many nurses. This final version of *Unthinkable Comforts* is something like a scar, left as a marker of this reflection.

### Unthinkable Comforts

I see you searching for your mother, your daughter?  
If I am she, I thank God I'm here for this.  
I am her arms, her caress and her smile, to keep you safe  
To be the comfort you crave.  
For you, I will be all you need and I will hold your old,  
Dying life and breath in my arms,  
Enwrapped together, entwined as one  
To comfort you and never to abandon at this  
New birth to your eternity above.

Others look on and pour scorn and judgement  
And see stark contrasts between you and me.  
Such to them is unthinkable.  
Uniform clad and hospital gown awaiting shroud,  
Separating, serrating the difference between you and me.  
They do not see the merged rainbow colours  
As we lie in reciprocity, of comfort, for both you and me.  
For, in this embrace I know we are both free to be  
As you have become such comfort to me.

Some time on from this encounter with Jane I remain moved by her experience and I believe the 'scar' I carry will remain now as part of me, etched onto my body of experience too. To me this speaks so powerfully of our undeniable relatedness as flesh of the world.

### Temporality, Relationality and Mood

#### The Test of Time

She wondered how long it would last  
This passion of youth,  
This pioneer spirit,  
All guns blazing

With idealist valour.  
Banner and colours unfurled,  
The battle cry on her lips,  
Passion-filled body powering into action,  
Strength and stamina  
To the end?

Or, would time do its work  
Leading the retreat  
From the front line,  
And extinguish the blaze?  
Flags at half-mast  
For former days of glory  
With a time-tired body  
To heave into  
Another day?

I wrote the poem *The Test of Time* after reflecting on Jane's whole script, and then more precisely on parts of it in which I felt she expressed both passion for, and also what seemed to be some possible lack of confidence in the sustainability of her passion to care until her retirement. As a more recently qualified member of staff, though certainly not young in years, she knew she had some sort of exuberance of youth at work in her, but it was through her hesitancy with her words and a sensed heaviness in her body, and a slight turning of her head away from me, that some implicit sadness seemed also to be speaking out. It was as though I could feel and see her concern, that her ability to care might wither or fade in some sort of autumn, to become more like the less passionate care she perceived in those who had been doing the job for longer than she had herself.

'It's just **such hard** work –  
you just **have** to keep going, like you are on a treadmill that just won't stop, it **never** stops –  
with all the notes (Jane 'air' types) - and laundry sorting out.  
But you get through it –  
somehow.  
I don't know how some people **do** it, who have been here 20 years –  
I don't know **how** they do it – they just show up each day, do what they have to do...  
But we get through it, somehow we do.'



At this point Jane was certainly not levelling any judgement on her colleagues, but rather I felt she was describing this as being the way of all things, the ending of the summer or the honeymoon and certainly by her use of the word 'we' twice in the last line, I felt that Jane certainly was identifying with her colleagues as part of a team. But she continued by saying, and a bit more forcefully,

'Some don't seem to get it. I **actually think** - things might be better if some people did leave and go home now.  
It's like they are **tired out** all the time, they seem slow –  
and they don't '**get**' dementia –  
maybe it's to do with culture or their training –  
**years** ago, or their age –  
not how we are taught now - in England.  
I know what I do is **right**. I just **hope** I will hold onto what I was taught and keep going with it.'

Although some of the words above relate to, and speak of, change and relationships, I think because I had a more profound sense of Jane's youthful exuberance, of passion in her caring and of being a champion and a soldier for a good cause, so evident throughout her whole text, I found that the battle imagery seemed more appropriate for my poem. This came to me more readily as I immersed myself into the transcript, remembering the interview and Jane's embodiment of this soldier image, gentle though she was throughout.

### Relationality

I was also aware that Jane maintained some strongly defined boundaries in her relationships between herself and other members of staff and also with the people for whom she cared. While I believe the detachment from the other staff was due more to their different attitudes to caring, I believe that Jane maintained some boundaries with people with dementia, reflecting those she may have been taught and from her experience. In *Unthinkable Comforts* the boundaries between Jane and the person with dementia appeared to me to be quite fluid, but in other places she made specific reference to these saying,

'I try not to have relationships with patients – I'm **into** boundaries – and I've learnt – **don't** get attached.'

From this it seemed clear that Jane felt some need to protect herself from emotional attachment and said, when talking about other short-stay wards, that she could 'protect myself **better** there' and followed this saying,

'I **never** go to their funerals...  
I **always** say, do not bring sweets in and **do not** spend your own money.  
It **blurs** the boundaries and my professional registration supports me in that - and **is** what is expected of me –  
(and I have made mistakes in the past.)'

Jane's use of the words 'patients' and 'residents' rather than referring to people by name, or as 'people with dementia' was evident throughout this interview, which I think drew attention to these professional boundaries, making it seem clear that she saw herself as a nurse, relating to a patient rather than as one person to another.

### Spatiality

Jane's experiences seemed to me to be profoundly affected by her environment at work as she made frequent references to the building. She seemed limited in the way she wanted to care for people, by the walls and by the doors, which quite literally did lock her into her person-centred care.

She described the building as,

'just **about** fit for purpose for the patients and the staff  
but we haven't got much physical space to move about.  
We hurt ourselves every day and I'm battered and bruised because we **don't** have **room**.  
It's not so bad on two of the bays though, because they can look out of the window –  
and we **try** to jolly it up -  
and soften the edges – but the beds are too close and we just pull the curtains around when we toilet someone.  
We **shouldn't have** to do that... we can't get the hoist in the bathroom...

but it's only temporary...  
it will get better.'

Later on in the interview Jane described the staff room as a 'dark hole' with 'stinking old arm chairs.' She continued,

'I don't even go there much. I go to the residents' sitting room that they don't use much and just sit there.  
I can't leave the building – there is nowhere to go –  
I'm **so** tired – but in the summer there is a bit of grass and I don't want to sit in the car.  
Sometimes I **need** to sleep - I am so exhausted on breaks.  
We put down sheets and then someone snores  
and I say "Was that me?"'

Jane was certainly not defeated by this even though she said she 'felt devalued' by the lack of comfortable space in which to take breaks and that she found it 'gruelling' to work in such a place. She seemed to be remarkably positive and hopeful for improvements to the building in the near future and summarized her conversation with me about this by saying with real acceptance, 'we make the best of it.'

Quite surprisingly Jane also described her work place as a place in which she said she felt 'at home'. I then wondered if by this she meant, a place in which she belonged in terms of her role, rather than it being a place which to her felt homely. I think the former seemed to be her meaning from her descriptions of her experience. I was really quite amazed by this summary and of her positivity and wondered if I could have such an attitude as hers in her position.

### Materiality

Jane made frequent references to what I have termed materiality, or things, to help describe her experience of person-centred care. Quite early on in her interview she made reference to 'The Green Army' her name for health care assistants. She said,

'They are **powerful**...

There are things they do that are **not right**, but they say –  
“We’ve been doing it like this for 20 years”, by which they mean,  
it was ok then and it’s ok now.  
How can I put it?  
They are well-**intentioned** –  
There is this carer, she says she was trained to do things a certain  
way – 20 or 30 years ago – so she **presumes** it must be right.  
The carer wants to wash the person in the bed, rolling her over and  
so on,  
but **I** want to use the hoist and take her to the bathroom and give her  
a **proper** bath - that she would enjoy.  
I am pleased that I am now qualified so I can speak from the  
perspective of knowledge and seniority –  
that it is in the **best interests** of the patient.’

More reflectively Jane continued,

“But it’s difficult -  
because I don’t want to explain all this in front of the patient –  
so I generally have to say something like “Go and get me something  
or other please” –  
and then I just do it.’

This spoke clearly of the tensions Jane faced between her colleagues’ ways  
and hers when it came to caring interventions and the lack of shared  
decision-making which should be evident in person-centred practice  
(McCormack and McCance, 2010, 2016). An even more vivid example  
followed as the interview progressed with an incident Jane recounted  
concerning a person’s teeth. This person had lost a lot of weight so her teeth  
did not fit so well.

‘So what do you **do** when the teeth don’t fit? –  
You put a **lot of glue** on them -  
and **you keep putting them back in**. That’s person-centred care.  
If she wants to have them back in **100 times** a day –  
that’s OK if **she** is happy with that...  
But the carer does the meals - and all the time I will come back and -  
**where** are the teeth?  
Wrapped up in a bit of paper on the table or the cupboard, or  
lost in the patient’s clothes.  
And the carer says  
“I find it better”...  
I say, if she wants her teeth, **give them to her!**  
I told the carer that this woman has 2 things left in her life,

her **teeth** and **knowing** when she needs to go to the loo.  
Most others can do that - so Mrs G's teeth are **important**  
and - if I have to hoist her **10 times** a day... and put her teeth in **100 times** a day -  
I'll do that!  
And the carer says - "Why don't you just tell her no?"

I was initially shocked by this care assistant's attitude. However, my feelings did lighten when, remembering Jane's small gasp, slight shake of her head and a very feint smile as she came to a pause after sharing this with me, I was able to find some of the humour which I think Jane was experiencing too. I was soon then able to write *She Finds It Better*.

### She Finds It Better

I heard her say so often,  
In tones so sure and so refined,  
With such experience on her side,  
(That really could not be denied)  
"I find it better if she does not have her teeth".  
And, so it seemed that was how it must be  
(Because she'd been responsible for teeth  
for so much longer than me).

Though, gnawing away inside,  
(Perhaps by those stray teeth  
which always found new places to hide)  
I heard another truth, a fact  
(That also could not be denied)  
That, if Mrs Giles (let's call her that)  
Seemed to want her teeth so much,  
(Loose-fitting and damaged though they were)  
Then it was her teeth she must have.

And so it has now become my daily act  
When others have left us alone,  
Out of kindness and care for Mrs Giles  
The hunt begins.  
The teeth are found,

Reinstated with pride,  
And Mrs Giles  
Smiles.

I can 'hear' the humour quite clearly now as I recall Jane's words and her embodied responses following her sharing this story of the teeth. The more I read this small section, one among many in which Jane described lived experiences through the lens of materiality, the more I could picture Mrs Giles. I imagined that, with her inability to use words herself, her teeth were doing the talking on her behalf and that eventually Mrs Giles' teeth began talking with Jane's voice and accent! I find myself laughing now at this very odd image but I think it certainly describes an example of experience so well which is both strangely funny and also deeply heart-warming. Jane was able to put aside others' ideas and probably what was the easiest and most practical solution to the problem with the teeth, to centre her care on Mrs Giles' comfort. She knew that the presence of teeth was life-enhancing for Mrs Giles, as 'ill fitting and damaged as they were' and knew both the cost and the value of the frequent and inconvenient searches. Mrs Giles was not the object of Jane's care, although the teeth were certainly the object of the frequent searches, but instead Mrs Giles was so evidently a person, a 'Thou' (Buber, 1937/1953) sharing an experience involving teeth. I also saw in this living experience a very clear example of what Merleau-Ponty described as the interconnectedness of our experiences which,

'reveal to us real properties of the thing itself, which is much as it appears and not some hidden substance that lies beneath our experience of its appearance.' (Merleau-Ponty, 1948/2004 pp. 17-18)

### The Essence of Person-Centred Dementia Care for Jane

Heidegger said that 'What something is, as it is, we call its essence or nature'. (Heidegger, 1971 p. 17) so for Jane, and the other participants, I sought to discover what person-centred dementia care was for them. For Jane her care was professional, clearly directed by her training, but it was also intuitive and openhearted, practical and kindly, and to some extent a type of caring that just seemed best at the time, but it was also boundaried, limiting the relationships she developed with people with dementia.

### The Meaning of Person-Centred Care for Jane

From Jane's transcript and my reflection upon it, I had the sense that person-centred care was for her something like a wordy legal document or contract to which she never referred very often, once it was signed and filed away. I sensed this to be something that was just there, in the background as some point for occasional reference. I also imagined that it was like the ID card that hung around her neck that probably hardly ever gets scrutinized by other staff, relatives or people with dementia. She would be many of the things a P-C ID would say on it, but it would be so much part of her 'uniform' that it would not be 'seen' as something distinct or separate and that she would not really have to 'put it on' as with her uniform.

I suspect that Jane's colleagues see her caring as an integral part of who she is and not as 'person-centred' but probably as 'different' perhaps accounting for the tension, judgement and distancing she felt from other staff.

Jane was one of the few participants who was familiar with Kitwood's writing on the subject of person-centredness, her reference to him summing this up quite well. She said,

'I don't think he was **that** great –  
with new ideas, and not worthy of so much attention.  
All this was known **well before** his time –  
it's all logical, common sense and just what you **do** if you **care**.'

### Jane: End Reflection

During the interview, Jane told me she had little opportunity to ever share details of her work with others and that she felt 'encouraged and lightened' by our meeting and the opportunity this provided to share some of her experiences from work and the feelings these 'churned up' in her. I was pleased to hear this, not only for Jane's sake but also because professional pride was working its way in me. However, I was not altogether surprised because I knew that very few nurses in Jersey attend support groups or have mentors with whom they can share work issues, concerns or problems. Apart

from this, I was also quite amazed at what a positively therapeutic effect Jane, and this interview, had on me. This was obvious within a very short time, and as I have continued to reflect on the transcript since then, I have felt that this therapeutic process has continued. I am aware of this on many levels. I felt encouraged by her, enlightened, hopeful and also felt good that I may have been helpful to her. This was positive, this first interview feeling like a 'cloudy and fiery pillar' (Good News Bible, Exodus: 14) to use for guidance and encouragement as I moved on to the second interview with Sally.

### Participant 2: Sally

And so I began the second interview with this sense of encouragement, believing even more in the potential of the method to yield the results I had hoped for. However, at about this time I had begun reading a book edited by Madjar and Walton, which drew my attention to the idea of 'unnaming and unknowing' (Madjar and Walton, 1999 pp. 8-9). I had begun this research knowing my own experience of person-centred dementia care, and my own history and beliefs and values were welcomed in this EHP approach, and while I knew these would inevitably shape the whole project, the idea of 'unnaming and unknowing' Jane was a new and unexpected concept I had to manage. I had to leave Jane out of Sally's lived experience, yet I so wanted to take her encouragement with me. Such an idea had not occurred to me until this stage but I began to see it as necessary to enable me to hear a new story, to find 'fresh possibilities for knowledge' (Ibid. p. 9) that would be true to Sally's individual experience. This was indeed timely reading. I did not know Sally's world of person-centred dementia care and I did not want to presume that I did because I knew something of Jane's. After some radical reflection on this I knew I needed to retreat as far as possible from any comparison of the two that might deafen the singing of a new song.



And really Sally could not have been more different as she greeted me, diving into the interview room and into the interview. It seemed to me like she was wound up ready to explode with her desire to tell me how things were for her! I was glad therefore that I was in some way prepared for this newness and that she was like a whirlwind, sweeping away the autumn leaves of the first interview.

I liked Sally immediately, I think because she was so relaxed and seemed very comfortable with whom she was, in her own skin, and with her work. I loved her enthusiasm to share too, from which I got the clear message that she trusted me. My judgement of her in this way, and all the more so because it was so speedy, did trouble me a little. There was no time to process this so I just had to accept it and hope it would not deafen, blind or desensitise me to anything that would be shared within the interview.

I asked her initially about her career and from this learnt that she had qualified as a nurse many years ago and had more recently added dementia specific person-centred training to this. She now has a senior position in a care home. Although Sally probably looked and dressed, and sounded nothing like Florence Nightingale, images of her sprang into my mind as I spoke with Sally. I was really quite surprised by this and had a chuckle to myself trying to push the image of Sally, dressed in a starched, black dress and white cap, out of my head!

As the interview continued however, it became more and more obvious to me that there were indeed some significant similarities, and that I was not therefore so far off the mark. Like Florence, it appeared that Sally was competent and respected, caring deeply for people with dementia, other staff and the standards in the home (Nightingale, 1859/1969 p. 35).

### Working with Sally's Data

I enjoyed revisiting Sally's transcript and did this many times following the interview, each time feeling almost immediately as though I was in her presence again and confident that I could work with the data. However, when it came to writing, I struggled to devise a way of working as well with the existentials as I had for Jane. This worried me. Some enlightenment as to the way ahead eventually came when I decided to make specific use of Focussing (Gendlin, 1978/2003). I gave myself time and space to allow myself to 'feel into' Sally's experience and to let my body 'speak' to me, eventually finding words that seemed to 'match' what my body was feeling. Through this process I'm now sure that I found Sally's experiences so difficult to write about, precisely because of the 'whirlwind' experience described above. She had left me 'battered' 'wind-swept' and with 'things out of place'. The time and distance I gave myself allowed me to 'sweep up' a bit after 'the storm'.

### Relationality

Immediately after explaining the interview process to Sally and giving her an indication of what I wanted her to share of her experiences she said,

'It's **hard** – About me – I **try** –  
I don't think anyone in life is better than any other.  
I **try** to do the same with everyone, whether or not they have  
dementia or not so I **try** to do it with the staff –  
and that's one of the hardest things –  
oh you are **taking the piss** – I show you respect but you haven't  
done it to me.  
**All the residents and the staff should be treated person-  
centredly.**'

I sensed from this very impassioned introduction that, like Nightingale (1859/1969 p. 28) Sally wanted to lead by example, but that she did not always feel that her actions were matched by those of the other staff. Her emphasis on the word 'try' had a sense of weariness to it but that this was a weariness fuelled by passion for the work she was doing and the way she went about it.

Sally then back-tracked in time as she described her upbringing, recalling her childhood as 'perfect' and spoke of her lovely, warm relationship with her parents and of how they instilled in her a respect, a word she used ten times during the interview, and care for others and of how actively they cared as a family for their neighbours. She then went straight into a description of her initial nursing education.

'Even in them days it was the - diabetic in bed 3 –  
and I used to think, **no** it's **Joe Bloggs** –  
and I used to get told off by **calling him by his name** -  
and I had to go to the office and give reports about the amputee in  
the second bed.  
But I thought they were **people**, not illnesses but in them days they  
were all illnesses - and I started remembering them as illnesses.  
Then I thought that was wrong and impersonal...  
and when I was qualified things were beginning to change  
and **people** got more respect then than the condition.  
So my experience and my training and my upbringing set me on the  
**right** path - so I never found person-centred care to be difficult.'

From these sections it seemed quite clear to me that Sally was a champion for person-centred care that focussed on the relational, but disappointed that some of the other staff (and from other sections of the interview, other nurses in other contexts) did not seem to 'get' person-centredness. Her relationships with both staff and people with dementia seemed to be built on her belief that all people are equal but different, beliefs seemingly instilled in her by her parents. As she spoke she referred to the people she cared for by their names rather than by definitions related to illness and seemed to show this too in the way she related to other staff. She seemed to know everyone very well and seemed flexible in her relationships with them, speaking French with some, using very 'relaxed language' with others and very happy to see the world as the people for whom she cared for appeared to do. The following sections from the transcript give some indication of these relationships.

'Just treat them **properly**,  
just **respect** them as individuals.  
It's little things like that - like Arthur who thinks he's in the war still,

and like talking French to Geraldine.  
**That's** respect.'

'Here, now, I can speak to someone **in their own way** if I know it's right for a person -  
and I can say to George, "Come on you old bugger, get out of that bed"  
and he'll say "Oh piss off and go and buy me a whisky".  
If an inspector heard me say that **they'd close us down** and say we had gone to pot!  
**Everyone** and **everything** affects each other.'

Because this interview took place within the care home in which Sally worked, and because there were several interruptions during our time together, I was fortunate to see Sally relating to other members of staff and the people for whom she cared. These interactions certainly bore witness to what Sally was saying.

### Spatiality

Sally made frequent references to space during the interview, often describing this as a 'home for the residents' in which she was a 'guest'.

'People don't just want you walking into their rooms –  
It's **their** home –  
And I'm a **guest**.'

'If someone came into **my** bedroom at one o'clock and said "Come on it's time to get up" I wouldn't like that!  
So I say to the staff that you **must knock** on the door first, and say hello...  
and Jackie doesn't kick off now if she's treated like this.'

Acknowledging this she did not deny the fact that she was both guest and worker at the same time in the same place.

'They **need** to be here - but I'm a guest - but without **them** I wouldn't have this job...  
It's not **my** home and it's not **really** a job.  
It's quite deep actually – - -  
Many people step back so they are **outside** looking in –  
not actually **here** in the **midst** of the care.  
Many staff still sit in their offices with the doors closed –  
and their attitude may be that **it is** a job.'

Sally then, in response to my asking how she would describe what she does if it's not a job said, 'A way of life I suppose with me, as a guest in their home'. She then talked of her responsibility to provide a comfortable space for the people for whom she cares which was 'well used', and talked about the dining room experience and the garden, which I could see was also being well used. Again this reminded me of Nightingale's belief in the value of fresh air (Nightingale, 1859/1969 p. 12) and of putting 'the patient in the best (place) for nature to act upon him' (Ibid. p. 133) but Sally stated firmly that 'It's not like running a hospital ward'.

### Materiality

Sally made many references to 'material things' throughout the whole interview and it was clear to me that such things were significant expressions of person-centred care for her. However, I also sensed she felt some need to justify the way 'things' were. Early in the interview she made reference to the fact that staff in the home did not wear uniforms. She said,

'I try not to have uniforms or a minibus and I told a carer off about wearing a low-cut tee shirt,  
and she said "**We should have uniforms**"  
and I said "Does that make you feel important?"  
and she said "Yes"  
and I said "**Well you are not.**  
There is no way you are telling them you are better than they are.  
**You are not.**"  
- She didn't get it ...'

When I initially heard this exchange I was rather shocked and wondered how well I would cope if I was the carer. Sally herself was dressed casually, as were all the other staff, with age and activity being the only things that distinguished the carers from the people they cared for. The last line of the quote above was said reflectively and almost as an aside which, as the interview progressed, became a recurring, almost catch-phrase statement for Sally and led to the following short poem.

### Badges Of Flesh and Bone

So it's the uniform you need  
To set you apart,  
To confirm and prove  
Your agile brain,  
Your status  
Above and beyond?  
But I beg you to look beneath,  
I beg you to see  
Humanity's ID  
Badges of flesh and bone  
Uniting, not dividing  
Shared stuff of life  
In you and me.

Later on Sally recounted the story of a carer who had been given disciplinary action while working in another care home for reading the local paper (JEP) with a person with dementia, and who wanted to come back and work in this home. Sally told me that the carer said,

“Sally, you would tell me off if I **didn't** sit and read the JEP!”  
In the evenings the staff are told not to do tasks, but to sit and be with the residents, watch the soaps with a glass of Bailey's until they want to go to bed...  
I'm trying to make it **normal living**, eating their dinner on a tray in the lounge...  
Dinner at 5 or 8 or in the lounge - or on a tray does it **matter**?  
I don't think it's rocket science.’

And then,

‘But these residents can cook in the kitchen, peel potatoes, when the legislation says they ‘couldn't use knives, they can't do this’.  
But **these** residents **do**  
**and** they go for walks in the rain, like ordinary people do.  
They say my thinking is ‘**unique**’  
but I don't think that.’

### Corporality

What struck me most profoundly while radically reflecting upon Sally's experiences and considering corporeality, was that she did not make any particular reference to her body or anyone else's. Rather, the sense I was left

with was of Sally as an embodied presence, much larger than life, truly the gestalt of being more than the sum of her parts. She seemed to me as though she brought this whole self into her work and ‘danced’ through this part of her life. When considering what this dance might be like I quickly came to the idea of the hokey-cokey, an idea which, once there, would not go! Sally seemed to put ‘her whole self in’ and in this way was ‘in the midst of the care’ and ‘that’s what it’s all about’.

### Mood

The existential mood seemed to tumble out of the lived experiences Sally described. She referred to finding her work ‘frustrating’ and ‘hard’ four times during the interview and on other occasions said she felt ‘angry’, ‘proud’ and ‘happy’. When describing her disappointment at the frequency with which she found new staff to be inadequately trained, she said she ‘didn’t **give a shit**’ about their qualifications as this didn’t seem to reflect their ability to care, saying ‘intuition should be possible’ and ‘experience’ had shown her ‘how difficult and different they can be in the (caring) context’. On another occasion it was clear that Sally was full of indignation as she described the following situation.

‘Someone came in this morning who was looking to place someone in a dementia care unit and she said to me,  
“I saw a **child**. Do you let **children** in **here**?”  
And I said, “Well **actually, yeh I do!**”  
**How dare they question it!**  
What’s **wrong** with having children in here!  
The residents **love** the kids - and dogs.

Sally’s desire for others to share her commitment to person-centred care was palpable in all she said and in the way she embodied the disappointment that people found it so difficult to grasp, that ‘people don’t **get it**’ (an expression she used seven times in the interview) when she found it ‘**common sense** and **normal**’. Even though this was so evident, I nonetheless sensed a relentlessness about Sally that suggested she would not give up on what seemed to me to be her lifework and vocation.

## Temporality

Within the interview Sally made many references to time, including the fact that she did not seem to divide her time into work time and off-duty time saying that,

‘Some people see this as a job, but it’s just **my life**.  
It’s **more** than a job.  
This is not really a **job** but away of life’.

My partner will say “What are they doing phoning at nine o’clock at night...  
This should be **your time**.”  
But it’s ok with me.’

Sally also seemed to be surprisingly relaxed about the way staff used their time with the people, praising the actions of a member of staff whom she said,

‘She picks up on little things...  
A resident will say “Give me a cuddle before you go” and she will get on her bed and lie there for **as long as** the person needed...  
It’s **not** about **tasks getting done at a certain time**.  
I don’t want staff to be things or task orientated.  
It detracts from **living** when it’s a task that needs to be done.  
That would not be the person’s agenda...  
but the cuddle **was, and there was time for it**.’

In other parts of the interview Sally’s described occasions in which people with dementia were evidently experiencing life as it was for them many years ago and seemed very able to join them in those times and places. Of Arthur she said,

‘He seems to think he’s still in the war some of the time and I can sort of see that in him so, if he’s there I will go along with it  
and if he’s happy there, with that, then **that’s good for him**.’

However she was also strongly of the opinion that people ‘lived in this time’ too and ‘into their futures’ saying that,

‘I’m also **not** big on having lots of 50s and 60s things around the



place...

People's styles can change and we shouldn't **presume** they are in a time-warp.

Although we do 'memory things', I don't really agree with memory corners either.

Why should they be encouraged to live in the past?...

No, **I can't** be doing with all that **memory lane stuff**...

They are in their time here, now, at their ages...

They can live well in their here and now if they are happy...  
and they can remember yesterday like we all do.'

### The Essence of Person-Centred Dementia Care for Sally

From my analysis of this data, I was left with the sense that the essence of person-centred care for Sally was care which was accessible and incredibly flexible to meet people's varied needs and was also practical, kind, common sense in action, peppered with some unorthodoxy and the refusal to put people in a box called 'residents'. She modelled this for other staff and worked hard to create the best possible environment for care. It seemed second nature for Sally, embodying Nightingale's idea that 'every woman is a nurse' and has knowledge enough to care for others (Nightingale 1859/1969 pp. 3-4). However, the care that Sally aspired to, even with these 'qualifications', was weighed down by others thinking and acting differently to her and the restraints of care policies and systems.

### The Meaning Of Person-Centred Care For Sally

From my time with Sally and further deeper reflection, it appeared that while Sally seemed to find it easy to see the world from another's perspective, to value others as equals, was able to provide a homely environment and deliver very professional care, because other members of staff did not value or even understand person-centred care as she did, it was 'hard' for her. However, while this seemed to leave her disappointed and even angry at times when others did not 'see it the way' she did, I believe the fact that she had studied person-centred theory in her training, validated to some extent, her way of caring. With this further reflection, and being drawn back to Sally's own words 'in the midst of', I also began to see her as a fountain in the midst

of a garden and like a conductor with her orchestra surrounding her, but both were struggling to have their full effect. Like these images, I got the sense that 'care' was in the midst of a room if she was in a room (speaking to me of Lévinas' idea of being human by living for the Other (Lévinas, 1961/1969) and Merleau-Ponty's (1945/1962) ideas of the body as the vehicle of being in the world) yet this was not all it could be.

### Sally: End Reflection

True to everything I have written about Sally the interview included several 'interruptions' from people with dementia, these offering me the opportunity to see the way in which Sally related to them and from which the following poem emerged. It incorporates Arthur's voice, with my own, and helps summarise the lived experience, essence and meaning of person-centred care for Sally.

#### Arthur's Place

She's here again today, the one waiting  
When they pulled me out of the trenches  
Who attends to all us young soldiers so well.

Harry, him in room two, tells me it can't be true  
He says "Arthur, it's the illness in your head"  
But he doesn't see it the way I do.  
He says "She's not got a uniform on" and  
"You're an olden not young"  
But he doesn't see it the way I do.

She dresses our wounds, she takes us out,  
She gives us our pills and we'll have a dance.  
But he doesn't see things the way I do.  
She runs this field hospital all spick and span,  
Homely too though vast and grand.  
But he doesn't see things the way I do.

"Arthur" he says "You're soft in the head  
With that thing beginning with A  
It's not the shell-shock that you say"  
But he doesn't see things the way I do.

She's here again today, the one waiting

When they pulled me out of the trenches  
Who attends to all us young soldiers so well.

### Participant 3: Monica

I really looked forward to the interview with Monica, not only because I felt so positive about the first two interviews and had growing confidence in the technicalities of the interview process, but also because our paths had crossed on several occasions at work, and while I knew her work place well, I knew very little about her. I was genuinely interested to know more and of her lived experience of person-centred dementia care. I reflected on the fact that this feeling was strikingly different to how I had felt immediately prior to my first interview with Jane.

#### Temporality, Corporeality and Mood

In response to my opening question concerning her nursing career, Monica gave a really full description of her extremely long working life, which has been almost exclusively with people with dementia. Within this she told me about the middle management position she now holds. It seemed, from the outset of this interview, that her career and its length was hugely important to her, almost defining who she was from a very young age.

Reflecting on the length of her working life she said,

‘There’s a lady who I look after who is 103 - and I often wonder how much time she has left –  
and how much time I have left.  
**Precious seconds** maybe, or longer.  
It’s a **big, huge** issue for me and I think this work makes you think like this...

You see their old, tired out, sometimes dying bodies –  
- - and you wonder - -.’

Monica seemed very ‘taken’ with her own words, which she had obviously chosen with great care. I found them intriguing because she appeared to be

communicating a sense of shared time and corporeality with the people for whom she cared. I therefore continued to reflect on this and other similar references throughout the interview, during which time I began to craft *Time and Ashes*.

### Time and Ashes

Time and disease  
Pick their way  
Through them,  
The near death living,  
Held onto only by breath  
Till all flesh is ravaged  
In it's hold  
To the bone.  
Wafer skin and  
Emptying eyes  
Tell the story of  
Time almost gone  
As the urn  
For ashes  
Waiting.

One by one  
They go,  
Replaced in time  
By another who  
Begins the cycle,  
Awaiting  
Their turn.

And for me?  
How will it be?  
And who will  
Watch and care  
Till ashes call?  
Am I, as them  
In younger frame  
Growing cold?  
Eyes fading?  
Skin thinning?  
No more song  
Or lover's hold?  
Am I too  
Waiting  
For death?

Although these words seem imbedded with gloom, I also had a sense of Monica's acceptance of the future. She faced its reality head-on and was not running away from it. Although dark, I found her, surprisingly, deeply comforting.

Her mood however soon became more animated when she began to describe having to do some study at the same time as working, which she said was 'actually stressing me out now.' She repeated this again quite soon saying,

'I'm getting really **stressed**...  
If someone goes off sick, I'll have to find **someone** to do it - or do it myself.  
I haven't had a day off now for **three** weeks and a usual day will be from 07.30 to 8 o'clock.

Monica described the effects of studying while working saying,

'You are so **drained** - it is so mentally and physically **draining**.'

However, of time, she also said that,

'It never seems long enough. There are **never** enough hours in the day...  
There is **never** a spare minute – no chance - - no chance.'

Interestingly, although Monica felt so pressurised and exhausted by the hours she worked, when I asked her about the future she spoke with some sadness about her future retirement. She seemed not to be looking forward to this and worried about having long days when she would miss the company of others she considered good company, including both colleagues and people in her care.

As I spent more time reflecting upon temporality for Monica, I began to see that she frequently referred to three distinct eras; the past, the present and the future, saying 'my time here has been punctuated by these changes'

referring to changes in the buildings in which she worked and the changing care practices within these. She described the past as,

**'unbelievable... There was no safe handling then... no lifts... and only one bath and no bed-screens'.**

She said she found it 'quite a shock' as a young nurse seeing patient's in 'identical velcroed dresses', their ulcers being 'dressed with non-sterile dressing packs' and mostly by untrained staff. With some sense of obvious despondency she said 'care had been like this until fairly recently' but with more enthusiasm she said that,

**'Times have changed, they are changing and there should be more changes.'**

There was a clear emphasis on her words 'should be' and she followed this by saying she had **'fought hard'** to see changes happen and that she was looking forward to working in another up-graded building, where she believed she could care for people with dementia better. She said,

**'I have, and am continuing to put my heart and soul into promoting good care for people with dementia – and I am hopeful – I am – that we'll have more improvements in the future.'**

However, from this it seemed to me that Monica was making no distinction between good care and her understanding of what person-centred care was.

### Relationality

Although I had secured a quiet room for the interview, a colleague came to find Monica just as we were beginning because someone in her care was leaving and wanted to say goodbye to her. It was lovely to witness Monica and this person in a warm embrace and to hear Monica say,

**'Good-bye darling. You've been here a long time and now you are moving on to your new home. I'll miss you.'**

Returning to the interview with more than a tear in her eye, I asked Monica about the person who was leaving. She again referred to this person, not as a patient, but as a 'lady'. In this context 'patient' would have been an acceptable term, but Monica clearly saw the person in her arms as someone other than a client, service-user or patient. She was a person who had become a close 'relative' for whom it was obvious that she cared deeply.

Monica and I spoke more about this. She said that although she could have applied for promotion on several occasions throughout her career, she had never considered doing so because she knew this would 'take her away from the patients' and that being with them was,

'the reward I get from the job. It's people hugging you when they are leaving...  
It's where I get my pleasure out of the job.'

She also said that she 'finds people **fascinating**, people's lives, their illnesses and what they have lost' and that she thought they were 'mostly loving and caring' and that you could 'get a lot back from them.' This was interesting to hear because it reflects my experience of the therapeutic relationship in person-centred counselling where benefits are mutual. Describing another person as a 'fascinating gent' she spoke of his time in her care and then his death, of the relationship she had developed with his sister, of attending his funeral, and even travelling with the family in the hearse. The gentleman's sister said she wanted this because 'she was the nearest thing to family he related to'.

It was interesting to note that throughout the interview Monica spoke warmly about each person to whom she made reference and it was evident she wanted to provide a good care experience and to promote a feeling of well-being. She seemed sympathetically present but perhaps her engagement was more as a care-provider and 'nurse' with responsibilities for her 'patients' which seemed to emphasise the dualities of nurse and patient in 'I-It' (Buber, 1937/1953) relationships rather than 'I-Thou' relationships.

## Relationality and Corporeality

As I reflected more on Monica's ability to foster close, lasting relationships with people with dementia and their families, I looked at this more deeply through the lens of corporeality again. What I began to notice was the ease with which Monica seemed to relate to, and get close to the bodies of the people for whom she cared. She was seemingly untroubled by their cognitive decline and very able to relate to them through the active, agential role of the body rather than through words (Kontos, 2005; Kontos and Martin, 2013) and what was of further interest was the way she was able to look beyond the exterior presentation of their bodies. She seemed to have none of the boundaries built by feelings of disgust, which tend to push people away (Miller, 1998; Beck, 2011) or of judgement of those in her care, rather, I could see in her a welcoming desire to care. This was made clear when Monica said,

'You see all sorts here, like the **lovely** guy covered in flies and so dirty and people whose bodies are **so** damaged and by age and dementia and those troubled people who die with you.  
It's hard sometimes but it is **my** work...  
and **my life**...  
and I do what I can no matter what the person looks like,  
no matter how ill they are...  
and I do still care after they have died.'

Monica also described some of the physical attacks she had experienced by other people, but it seemed she was able to look beyond these saying that,

'I **manage** just by **accepting** it as part of the job and knowing that they aren't **intentionally** being so aggressive.  
That helps me...  
They may be fighting for what they think is their **life**.  
We are attacking **them** basically...  
but there again, there are other parts of the job that **make up** for all that.'

It seemed Monica had the ability to see the world from the perspective of the people for whom she cared and to accept their embodied responses to the



differing perspectives they had. This spoke to me so much of her embodied, relational, being-in-the-world of others.

### Mood

What struck me most profoundly about this existential for Monica was the whole range of moods she experienced and so honestly described to me. She seemed at ease with herself, very accepting of her situation and her limitations, hopeful for the future and very aware of not only the stresses and strains of being a caregiver but also of the benefits she received in return from the people for whom she cared. In response to this I wrote *Reciprocated Care*.

#### Reciprocated Care

Sometimes I feel so tired,  
Stretched-out to my limits,  
Thinned-out by it all,  
With never enough  
Air to breathe  
Or time to exhale.

But then, distracted  
By what I see, I feel  
My heart take a leap  
And their need,  
So painfully real,  
Tells me I am alive.

And so I reach out,  
Welcome, embrace  
And feel in my giving  
My burden is lifted,  
My hope renewed  
And the air is sweet.

### The Essence of Person-Centred Care for Monica

Because of Monica's limited references in the interview to material things, apart from the building in which she worked, and her nursing practice, arriving at an understanding of the essence of person-centred care for

Monica was relatively straightforward. I suggest that what makes person-centred care what it is for Monica is her focus on the person at the centre of her care and her relationship with them. Her conversation with me was almost entirely person or patient focussed, clearly revealing the importance of the relationships she endeavoured to develop, but with some inevitable separation because of her identity as care-provider and them as a 'patient'.

### The Meaning of Person-Centred Care for Monica

I spent some time working reflexively at this point because what seemed to be seeping in and dominating my thinking here was my own assessment of Monica's caring, rather than my focus being on interpreting meaning from her lived experience. I felt perhaps that my loud singing was drowning out Monica's own quieter voice. So, slowing down and returning to her whole transcript I waited to hear her quieter, whispered singing and allowed some of her embodied silent expressions back into this analysis.

I was unexpectedly struck by a deep sense of Monica as a loner, having talked very little about her colleagues and managers, and then recalled that every time I had ever seen her at work she was only ever with the people for whom she cared and never engaging with other members of staff. She seemed 'alone'.

Nevertheless, I could see and feel that Monica's underlying peacefulness, even with her aloneness, in her time-pressured, busy workplace, was derived from the perfect fit of her compassion and kindness for others, with her work, giving her the opportunity to be authentically herself at work. This meant that Monica seemed to be living out a vocation, a word I was surprised to find myself using, not having considered it until this point. This left me wondering if she actually ever considered her work as 'person-centred' (apart from during the interview with me) this perhaps being just the way she was, and that even if she was not a nurse, and had never heard of person-centred care, she would be 'person' centred.

## Participant 4: Katie

Katie is a relatively young, registered mental health nurse, with considerable experience in the field of dementia care and holds a position with some management responsibilities. Like Monica, her work is mostly with people with dementia but also includes some office-based duties. As I introduced myself, and a little more about the research and the interview process, I got the impression that Katie was strong and confident, yet also perhaps a little nervous too, which I thought was strange given her obvious willingness to take part. I could not fathom the cause of this and because none of the participants before her had appeared to be so nervous or apprehensive, this observation did trouble me a little. However, because she seemed quite interested in the research I decided to go into more detail about this, hoping that by diverting attention to this rather than the interview, she would feel more at ease. I spoke a little about my background and then about the methodology, making reference to the lifeworld existentials that I would use for the data analysis and of these being lenses to help me discover more about peoples' experiences of person-centred care. The explanation seemed helpful and this, or perhaps just the passage of time, or her growing confidence in our relationship as participant and researcher, seemed to have the effect of physically relaxing her. Without a breath it seemed we were off into the interview as she said,

'I think the body one **jumped out** for me as you were talking.'

Katie then continued talking about her uniform and those of her colleagues, in which I saw relationality become inseparably entwined with materiality rather than 'the body one' Katie suggested.

### Relationality and Materiality

Katie spoke at length about her uniform, its distinctive colour and of her colleagues' uniforms, each time relating this to their position in work, the

colour communicating the type of work they did or their level of seniority. Katie felt such distinction was important for everyone saying,

‘I’m a **nurse** and they are **sick**, so it’s maybe good for reality orientation...  
For a long time I was the only person in blue  
and I think **that** set me apart.  
Most people understand the hierarchy - that I was in charge,  
and the relatives and patients and other staff would come directly to  
me, the **figurehead**.  
The uniform has an **impact**.  
**You** have the answers – or **you** are the person I can talk to who can  
get things going.’

While Katie, from the outset of the interview, made her support for person-centred values very clear, she obviously adopted a very different approach to the wearing of uniforms to Sally. Katie believed that they had a positive value in defining the roles of the staff for people with dementia and visitors alike and helped ‘orientate people to their reality as patients in hospital wards’. She continued,

‘They look to **me** to have the difficult conversations.  
I take the difficult ones,  
but I see myself as ultimately for the patients...being a patient  
advocate...  
Like with Pat in those last difficult weeks, meeting the family and  
talking about the DNR and not moving her to the General...  
**They are difficult and they take their toll** emotionally...but...  
because I’ve had **so many** of them I’ve learnt the best way to handle  
them...  
and there are different ways for different people...  
but **being the figurehead** does lead me to be...  
and with that comes very challenging situations where um...  
and not everyone will be happy with what I am saying.’

I found the way Katie described herself as a figurehead to be really interesting, and from which I got the sense that she was heading up her team in a lonely place, isolated by her responsibility. I began to feel some sadness for her at this point and sensed a gradual slowing in our conversation which began to seem less like an interview and more like, not quite a heart-to-heart, but as though I was beginning to join her somewhere in her world and that

we were no longer at opposite sides of the room. Later, as I reflected more on this, the image of a figurehead on an old fashioned sailing ship came to mind and grew in detail. Gradually this dominantly positioned figurehead became Katie. She was there, embodied in the wooden carving with, quite literally, her hands tied into the body of the vessel itself. It seemed she had become her role and somehow fixed in it. From this image and reflection I wrote the following poem.

### Figurehead

Figurehead,  
Figuratively speaking,  
Leading,  
Pointing  
Towards  
The way  
To go.

But cold  
There, alone,  
A head with  
Disabled limbs  
Tied into wood,  
Stilled,  
Quietened,  
A figurehead  
With little sway.

### Mood

What followed on from the descriptions Katie gave about the uniforms and the functional role of her uniform in particular, was what seemed like a clear shift from materiality towards the existential mood in Katie's experience of her person-centred work.

She described a situation as 'absolutely horrible' in which she was unable, to comfort or help a person who was tearful, distressed and desperately searching for her husband, who Katie knew had died some years ago. She said,

‘I just had to **move away** and **leave** her to work through it herself...  
and it was **so hard** to do because as a nurse - -.’

At this point Katie was clearly unable to continue talking and looked very much as though she was re-experiencing the emotions of this situation again. I therefore continued by saying,

‘You wanted to be making her feel better?’

Katie seemed relieved that I had stepped in to finish her sentence for her in this way and then continued,

‘**Yes, making it better, dealing with the problem and solving it.**  
That’s what nurses **should** be doing...  
This is at the **core** of **all** us nurses, and that is why I am conscious of using the term patient.  
There are a **myriad** of different terms for people - clients, service users,  
but at the heart of it I am a **nurse** and I work in a **hospital** and there’s a role there...  
but I **want** to be as PC as possible and that is difficult, **really difficult** sometimes...  
the conflict and the confines...  
We are able to do it to some extent in a PC way, but to be **honest** we are not perfect...  
It’s difficult to do that in a **clinical** environment.’

I spent some time with this part of this interview and wondered if it was not so much that she was unable to comfort the distressed patient, but rather that she interpreted her ‘position’ as one which did not allow her to do so.

### Spatiality and Materiality

Katie then began to focus more on the limitations of the building in which she worked and how this in turn determined and limited the way she was able to work. She expressed disappointment that ‘her patients’ had so little private or personal space in which to express themselves or take refuge when they needed to be alone. She said,

‘Not many can have their own rooms so there may be several sharing - so they can’t have too many personal possessions - so **that’s**

difficult...  
but it's the little things we **can** do...  
giving people a choice and getting **them** right,  
recognising things that are important to them,  
and **must** become important to us - and we'll work with that.  
They may not be able to have a lovely room with all their possessions  
around -  
and we're not able to create something bespoke for them -  
but I **really believe** it is the little things.

From this I could hear more of the deep concern Katie had for the people for whom she cared but also of how she felt unable to deliver care as she would like to do because of the limitations of the building and its design. She seemed to be saying that while some elements of person-centred care were not dependant on design, other aspects of the care, which she aspired to deliver, were impossible in the context.

Katie followed this with lovely stories about two people in her care. She talked about a 'relatively young patient' who had, until recently, had a dynamic career which took him all around the world, but whose dementia was now quite advanced and who had significant problems with fluctuating outbursts of anger. She said she thought this was due to his 'significant distress and not being able to explain his feelings' saying that,

'So, I **try** to give him what I think he needs.  
I **know** that he likes one-to-ones and sitting in the office - and that, in his **mind** - I think he thinks he is one of us –  
so he sits with us and writes his notes.'

The second person was an older lady who had been a housekeeper for most of her working life. Katie said that knowing about this helped and that she often gave her baskets of laundry to sort out and even though it took her most of the day doing this, she always appeared to be happy in her work and peaceful in the sleep that followed.

Katie shared these stories with evident pride and satisfaction in her tone and following this proceeded to share more details of her personal life with me. I

wondered if that, by reminding herself of these good-news, heart-warming stories, she felt more able to delve deeper and to share more with me.

### Temporality

Much of Katie's more reflective sharing related to temporality and she, like other participants, described care in the past as being less person-centred. She said,

'We are not perfect and **all it takes** is for staff to go off sick and we can't get cover and things get 'lost'...  
but it's **my job** to make sure,  
no matter how tired,  
that we don't go back into the **old nursing roles**...  
The **old** way is when we are busy and stretched or under-staffed.  
We work 12 hour shifts and **never** get the breaks we are meant to get...  
I'm not saying about the hours because I don't **begrudge** it you know...  
and I do want to point out that the staff **do go above and beyond**.  
We are on our feet for 12 hours.'

Then, in response to my question asking why she worked so hard and such long hours, what the meaning of all this was for her she said,

'I suppose it's a mixture of things...  
It's my nature, you know – nursing was **high up** on the things I wanted to do when I was younger.  
My mum was a psychiatric nurse and then became unwell, so I became her carer as a child - so I think it kind of came from there...  
And I think - **that** person could be my mum, or my nan...  
**that always comes back to me**...  
It's in my heart too.  
And I do feel myself getting upset...  
Janice's daughter is my age, and she's sitting there now beside the bed waiting to say goodbye –  
**and that could be me.**'

Katie then shared other information about her family which certainly touched my heart, and then continued,

'But I love my job, I **really do**...  
being there and helping, **if I can** - people through the most difficult stages of their life...



but there is some selfishness in there too because...it makes **me** feel better about **me**.

But it always comes back to **time**.

If you haven't got the **time** to do what it suggests, you are seen as negative because you are not following those principles.

I **agree** it is about being more creative - and thinking in different ways – and using the time differently - and being adaptable...

but **actually** the **reality of life** and delivering that theory is **really, really hard work**...

and - when you are fresh - new in the morning - it's easier than when you are tired at the end of a 5 day week...

You put yourself in **their shoes** and - when you stop being able to do that you just **have to** walk away.'

By the end of the interview I had the clear impression that any sense of nervousness that I had detected in Katie had passed and she seemed to be less of the 'full-figured' confident figurehead but sounded more like a young girl talking about her aspiration to be a nurse who would make people better when she grew up.

#### The Essence of Person-Centred Care for Katie

In the closing minutes of the interview, Katie made the essence of person-centred care for her very clear when she said it was, 'putting yourself in their shoes as much as possible' and with as 'thick a skin' as possible and 'being the nurse you are supposed to be'. I think this was the essence of her work, which was not so much a way of being or a philosophy of care, but more of a marker for 'doing' care well, which mattered to her a great deal. It was interesting however that Katie had added in the words 'as possible' and 'supposed to be' which left a clear impression that this was not always achieved and that there was perhaps more that she knew could be included in this list.

#### The Meaning of Person-Centred Care for Katie

For Katie, using the term 'person-centred' meant nursing care in her place of work was, by definition, 'gold-standard'. However, I felt she carried some sense of guilt for this not always being achieved, and while I believe she did not bare this all personally, speaking as she did at length about the

limitations of the building, staffing and other resources, she was rather apologetic to me. I wonder too if the nervousness I initially sensed in her was because of this, fearing this being revealed by the interview process. I am however, very certain, because of the growing ease and depth at which Katie shared with me as the interview progressed, that she did not feel any sense of judgement by me. She seemed increasingly more relaxed saying she was pleased to have had the chance to take part in this research and that,

‘It’s things like **this** which helps to develop our practice. **Theory** is all very well.’

### End Reflection: Katie

This interview was long, but in every part of it I saw in Katie a truly professional nurse, a clear figurehead, and someone with a generous heart. I was left feeling that, if in the future I had dementia and found myself in need of professional care, I would want someone like Katie overseeing this. I imagined I would feel safe with her, though perhaps occasionally missing a warm hug. I was left with a sense that Katie needed, for some reason, because of some insecurity perhaps, to present herself and role as so ‘professional’. It occurred to me that, as Sheard suggests is the case for some professionals, she might have been ‘distracted’ by the concepts of person-centred care and perhaps struggled to ‘connect all the elements involved’ (Sheard, 2004 p. 22). It seemed that her place of work with the limitations of the building and its function, did not lend itself well to person-centred care and that knowing this, Katie might have felt she struggled to deliver this care as she would like and as perhaps was expected of her.

### Participant 5: Sam

I had not met Sam prior to the interview but knew her place of work well. What struck me straight away was that she seemed so young and rather shy and perhaps a little daunted by the situation. Her anxiety was palpable so I

made every effort to put her at her ease, not wanting to seem like one of her managers, or to seem too controlling with any applied research techniques, but for the situation to become one where there was equality between us and where we could be more like co-workers (Beuthin, 2014 p. 128) discovering more about person-centred care together. I felt that what we were engaged in was conversational and quite natural, but I was sure Sam, although happy to contribute, did continue to feel some anxiety. In my work as a counsellor I am used to people feeling anxious as they close the door and enter the counselling space for the first time. I understand this and I believe I manage such situations relatively well, but Sam's anxiety made me feel uncomfortable because, in this context, there would be no opportunity for our relationship to develop over time. I therefore felt I needed to care for her gently throughout the interview.

I could not develop any deeper reflection on this or work reflexively with it as the interview progressed, but afterwards I made this a priority and wondered if my concerns for Sam were heightened because she was exactly the same age as one of my daughters who also works with people with dementia. I wondered if I was feeling the anxiety any parent would feel seeing their child out of their comfort zone and facing a new challenge. I would want any researcher interviewing my daughter to be kind and conduct the interview to the highest standards. What I did notice during its course, and which was revealed clearly in the transcript, was the balance in our sharing. In other interviews there was very little need for me to direct the process, but Sam needed more of this, though once reassured and encouraged to do so, she always responded in detail and offered valuable descriptions of her experiences.

### Temporality, Corporality and Spatiality

What struck me very much about Sam's experience was the temporal and spatial ordering of her work around the temporal and spatial ordering of the routines of the people in her care, directed by the needs of their bodies,

ideas introduced to me by Kontos and Martin (2013 p. 289) and which, in Sam's descriptions did seem perhaps 'homogenised, collective and distant' (Twigg, 2000 p. 104). I felt this because Sam never made reference to people's names, she seemed to make generalisations for all people in her care, and did seem to prioritise people's physical needs to be 'toileted' or 'fed' or 'calmed', rather than expressing much about her relationships with them or her feelings about them. For example she said,

'You **have** to make sure patients aren't on the toilet for too long, and stuff like that...  
and like washing and dressing – you've **got to make sure** they are alright,  
not sitting uncomfortably...  
and doing activities with them - activities is a **big one** –  
and cleaning up vomit – I find it's nice that I can do **that** sort of stuff  
and feel like I am doing them (other staff) a favour.'

Some enlightenment for the reason why Sam's caring seemed perhaps less person-centred came after further immersion into her experience through the transcript. Later in our conversation she had very briefly mentioned how she felt when someone dies. She said,

'The **most** upsetting is when someone passes away – that's **difficult** and you've made that relationship - - -.'

At this point Sam seemed a little embarrassed, maybe guilty, paused significantly and looked down. She then continued,

'**They** say you should treat all patients the same - **and you do** –  
and you don't - (said very quietly)  
**some** have their individual needs **too**...  
The patients and the relatives...  
You get used to them over time – them coming in, and you making them a cup of tea - and you know, just chatting...  
especially if they can't talk very well -  
You put on your smile  
and you say  
'She's had a **nice** breakfast – and start a conversation off –  
and it's nice – it's nice.'

I understood from this that at some stage Sam had been taught that she should treat everyone the same and not establish special relationships with anyone. I sensed that, as a relatively new member of staff, she was keen to follow these and other instructions (as highlighted by Manley, 2004 p. 54) and was focussed on the tasks she was expected to complete in a designated time. She seemed to have been told what to 'do', but not how to 'be'.

My sense of this developed as Sam continued to speak about her life. She had previously been employed as a domestic but a manager, seeing how well she got on with people, suggested she considered a new career. She pursued this and now holds her position with obvious pride, saying she had,

'**never** expected to be able to get such a **good** job'.

It seemed that she derived the affirmation she needed, that she was doing a good job, from being able to follow the instructions she was given to do certain tasks and getting them completed in the allocated time. This prompted me to ask her directly about person-centred care in her place of work to which she answered,

'Oh we have that here, we **do** that.'

When I asked Sam more about this in relation to specific person-centred care training she said that,

'We didn't have **much** training 'til we got more dementia patients,  
and then we **did** - but it wasn't much.  
I've learnt about hoisting, how to roll people,  
stuff like that and how to feed somebody.'

Sam continued to speak with the same pride I thought I had heard earlier, as she spoke about her training and of 'being trained' but from her descriptions it appeared that she had had no training in person-centred care. I expect therefore that she had probably not had much chance to explore what this meant in the context of her work, or to consider if her caring aligned with her

beliefs and values, which McCance et al. (1999 p. 1394) suggested was necessary for its successful application in practice. Instead she seemed to do what she was instructed to do without question or reflection.

Leaving the conversation about training, I then prompted Sam to tell me something about the space in which she worked and quickly described this as '**noisy**' developing this by saying,

'Sometimes it can get **quite noisy** and you have to take your patient to a quieter bay...  
There can be too many in the room - and I find sometimes...  
um...um...  
someone will have the TV on, and someone music and another wants to be quiet.  
It gets **too much** sometimes and someone will start kicking off - -  
and, and - um - um - tries to get out of their chair - or something like that -  
and you have to try to calm them down - and take them to a quieter bit.'

When I then asked if people went to their own rooms if they wanted some peace, Sam very hesitantly said,

'The bedrooms are locked and I think it's what's wrong with the patients -  
if they are on levels 1, 2 or 3, then you **have to** make sure you can see them-  
and you **can't** see them if there are only a few of us and we are in the day-room.  
  
We **have to** keep them in sight for their safety -  
It's all down to staffing again.'

From this part of the interview I got the clear impression that Sam did not like the fact that people spent the day in one room together. When I asked her if she had discussed this with senior staff, she quietly just said 'No'. As I reflected on this I remember her voicing the section above rather quietly and more quickly than most other parts and remembered her looking down at this point. From her verbal and embodied responses I felt Sam thought it unthinkable that she should bring up any such issues with other staff and that

it was not her place to do so, even though she seemed uneasy with this practice, seeing it perhaps more like the panopticon to which Gubrium and Holstein (1999 p. 533) referred. I think she was also unsure if she should be sharing these thoughts with me.

As I worked reflexively with this, I did feel a sense of sadness for Sam, as I believed she imagined such conversations were not for her to have and certainly her power to influence. I felt angry too because I was sure Sam did not feel comfortable in this practice but just had to do it anyway. I saw her being gagged by her view of herself and by not being encouraged to discuss her work with a mentor or supervisor or in a peer support group.

This reflection and reflexive work led me to write the following poem, which I have called *The Shape Of The Day*. It is focussed on what I interpreted as Sam's ordering of time and space in which she manages others' bodies. Alongside this I was left with the image of her striving to keep a smile permanently etched on her face, which seemed so predominant in her experience of person-centred caring.

### The Shape Of The Day

The day begins early as always  
And it seems it's only me  
Awake in this sleeping world  
Pacing well-worn paths to work.  
But once in there, it's another world.  
My coat is off and my smile is on  
Set ready for streets already alive,  
Busying up and buzzing  
With familiar sounds  
Telling me who's around each corner.  
And this symphony of humanity  
Calling out for attention and  
Calling to attention  
Stretches out the day before me.  
It's getting them up –  
It's washing –  
It's dressing –  
It's helping them eat –

And other more personal things too.  
Then it's the undressing –  
It's more washing –  
But it's always smiling –  
Till it's time to go  
Twelve full up, full on hours later –  
Though it seems only two or three,  
With time having flown like the wind  
Taking me back to darkened streets  
Now with tired out feet  
But a smile that lingers on.

### Relationality and Mood

I have included relationality and mood together for Sam because to me she seemed lonely at work, a little set apart from the team, keeping herself and her feelings to herself. However, she seemed diligent and committed to her work and the people for whom she cared and struck me as someone who was trustworthy and honest and who clearly took pride in all she did. I wondered if some of her distance from the others was a consequence of her high respect for those in positions above her and the humble view she took of herself because of her background, detailed descriptions of which she shared with me. I also considered that this might account for her willingness to unquestionably accept direction from them. I got a sense of this when she said,

'I keep it in my head - what **they've** said and what I've got to do'

and also when she frequently used expressions like, 'you're **supposed** to do', 'you **have** to' and 'you've **got** to'. I am left wondering from this if she felt any of the anger and sadness I felt for her, in relation to the issues of spatiality I have discussed above. Sam did not give me very much sense of her mood or emotion suggesting perhaps some Cartesian splitting of these off from her body's expression, which might offer an explanation for my observation which seemed quite contrary to what Merleau-Ponty suggested usual for the observer (Merleau-Ponty, 1948/2008 p. 23). I wondered too if Sam wished she could be more person-centred and wondered if she may



thrive in another context where person-centred care was promoted and she could be enabled rather than directed.

### Materiality

There was one part of the interview however, in which Sam did become more animated. This was when she talked about a book she had made for a person with dementia and as she described this she seemed to me like a gushing, bank-full river. She was almost bubbling as she said,

**'Yeh, I remember**, we had the one lady who other people said "she can't talk" **so I thought, right**, I'll try and do a picture book of things, so I went around taking pictures of things and I put them in a book, I started with two things first, a cup of tea and a biscuit, I started easy and I put them in front of her and I said, would she like a drink and a biscuit, **and she looked at me and smiled** and um...um...**and she did point**, so from that day I did **more**, and then one day, **clear as anything**, she said "**please**" **she just had one little word and it was great!** so, **I think**, it is just...  
sitting with patients, maybe, and just getting into what they are thinking.'

I have made this one long sentence quite intentionally because, as I transcribed this section, it was really unclear where Sam had taken any breaths! In her obvious pleasure the above just seemed to gush out. As I reflected more on this however I felt heavy-hearted. This was the only place in the interview where Sam seemed courageous enough, or was given enough time away from her planned interventions, for any spontaneous interaction. Snoeren et al. (2014 p. 2) suggest such spontaneity is a means for achieving cultural change and for practitioners to become more person-centred. I hoped Sam would get other such opportunities.

### The Essence of Person-Centred Care for Sam

Person-centred care for Sam appeared to be directed by others, with little freedom for her to be flexible or creative. She had tasks she was required to do at given times, which focussed on the dementia or a problem that needed to be solved, rather than on the person. The essence of person-centred care

for Sam was therefore more 'by the book' than by the person, it was restrained, which may be the reason she appeared to miss out on being sympathetically present, was inflexible, lacked creativity, was unshared and being directed by others, was perhaps lacking personal authenticity.

### The Meaning of Person-Centred Care for Sam

Although I think Sam did feel some stress in her role from trying hard to achieve all she was asked to do, I am certain that person-centred care also meant she could hold her head high with the dignity she derived from being part of a professional workforce. Although she did not seem to have had any person-centred skills training, she recognised it as a model that was highly valued and which therefore, I believe, added further weight to her professional pride. I also consider that the demands of her caring role might have initiated what I perceived as some separation of her embodied behaviours from her emotions. I imagined that Sam would be self-conscious of others' judgements and that she might therefore attempt to conceal her emotions in an attempt to prevent the alienation that Merleau-Ponty believes happens, when others discover our inner thoughts and feelings (Merleau-Ponty, 1948/2008 p. 22).

Furthermore, even though I feel she was unable to challenge others at work because she did not have the confidence, ability, experience or permission to do so, I wonder if she also therefore carried a sense of guilt with her into her work-place, knowing she was not able to deliver the best care, being restrained in caring both 'for' and 'about' the person with dementia (McCormack and McCance, 2010 p. 25).

## Participant 6: Julie

### A Day's Meaning

Considering,  
Contemplating,  
Configure-rating  
The day that stretches ahead.  
A constantly updated,  
Refreshed and refined  
Activity map in my mind  
To tell me who's who,  
What time, in what place,  
How many, how long  
Or how few.  
Who's in and who's out,  
Who's sick and who's about -  
I consider each thing, each call  
From this laden desk  
In the throes of it all.  
Allocating,  
Assessing,  
Never digressing  
From the tasks  
That I have to do.  
Apart from one thing  
That pulls me back in  
And temporarily  
Distracts from this all.  
It's a smile on a face  
That blesses this place  
And leaves meaning  
Gives soul.

Ideas for *A Day's Meaning* tumbled into my mind as I found myself immersed back into the interview through Julie's transcript. Because of this almost immediate response, I felt I should begin this section with this poem to introduce you to Julie, as she re-presented herself to me. She is an experienced senior staff nurse who works in a context caring for people with complex needs associated with their diagnosis of dementia. Although I had made it clear in the introduction to the interview, that I wanted Julie to talk about all aspects of her person-centre care, almost all of the interview was dominated by descriptions of the structure of the workforce and her position

and organisational and planning roles within this. I found it surprisingly difficult to negotiate her away from these subjects. She described herself as being 'generally the nurse in charge'.

### Temporality

'Time is constantly in my mind' was Julie's opening statement in the interview, from which I immediately gained some sense of its significance, but further, by her use of the word 'in'. Because it is perhaps more usual to say that we have things *on* our minds, I felt a deeper significance in this introduction. She continued,

'So I guess, in terms of time,  
I guess **I'm** responsible for the time management of the shift...  
So, usually right at the very **start** of the day,  
my first job is to um -  
decide who's working where,  
breaks,  
looking through the diary at the events that are occurring -  
and to make some decisions about how things are going to run that  
day...  
if there are some escorts, I'll make some decisions on that...  
and we have various people coming in, so it's trying to balance that  
out-  
But it'll take one incident though to **completely throw out** our timing.'

Julie continued talking about the structure of her day and those of the other staff with whom she worked finishing by saying,

'So I plan ahead and try to make sure I **stick** to that timing, not just for me but for other staff as well because what we've found, over the years is that -  
it is **quite easy for staff to drift**...  
Taking **too much time over tasks** and then things don't get done...  
**Everything** is geared around the patient,  
but it's trying to make sure -  
**everything that is really important is actually done**  
within the time  
we have.'

When I asked Julie to give me an example of such a situation she said,

'It's just around the day-to-day activities, like making sure people are assisted to be up - all the ADLs obviously. These are in the basic model of care in person-centred care, **to make sure** that happens, that everything that **should** be done, **is** done... So - what I find is - **I never really stop thinking** – about what you are **supposed** to do.'

Our conversation continued about activities of daily living and how helping people with these was scheduled in to her day and then about what happens when something unscheduled occurs.

'**All** the day to day stuff - that's the routines - so we are staffed for that, but if anything happens that breaks into that routine, then we can **immediately add on hours** of time... and **all it takes** is for **one person** to be off sick and then you have to spend **more time** looking for **someone else** to come in.'

From this I felt that the culture of care in Julie's workplace seemed predominantly medical, with its priority for good physical care, safety and efficiency (Biernacki, 2007 p. 178) even though Julie said she 'did' person-centred care, and certainly all supporting literature for such care settings in Jersey are described in health literature as person-centred. I wondered if perhaps she felt she did not have enough time to 'do' any more than her job, or if perhaps she had not been encouraged to move from the model in which she had been trained, to work in a more person-centred way (Ibid. p. 179). I have included a fuller reflection of this in Chapter 8.

### Relationality

I think that because Julie placed so much emphasis on her nursing practice and the ordering of tasks that needed to be done, I found it difficult to see beyond this to examples of her lived experience of person-centred nursing care through the existential of relationality with either staff or people with dementia. At one point when she described her work as 'managing' people, this absence of relational depth seemed striking to me. She said,

'We manage people here. These are patients who, because of their behaviour through illness, will not be managed elsewhere.'

That's our **primary function** really.'

Following on from this we talked together about the other staff and her relationships with them. Julie said,

'I think we are a team, and some people are better than others in terms of aspects they bring...and various strengths and weaknesses, and so when I plan a rota for the day, I know what staff I can put in different situations.'

Both in the interview and later working with the transcript, I found myself surprised to hear Julie talk of 'putting' staff in different 'situations' and missed the more person-centred emphasis in this sentence which I would have expected to be more like, 'I know Mrs Jones gets on well with Kelly, so I'll make sure she can spend some time with her today'. Because this made such an impression on me, I wanted to develop this conversation and asked Julie to tell me more. She said,

'So it's about knowing the best staff member to get to deal with different things.'

Because the words in the earlier part of the interview had already struck me so profoundly, the words 'get to deal with' and 'things' (which I understood to mean people) boomed out. They demanded my consideration and I was aware that I began working reflexively with this during the interview itself and that my body responses may have been revealing some of my feelings. I really hoped though that this was not as apparent to Julie as it was to me. I became aware of a real battle between my bubbling disappointment in the way I heard Julie speak and my own views, established through my own experience as a person-centred counsellor. Once aware of this, I made every effort to bracket off my own views and judgements to re-focus my attention again on Julie's experience, but this was difficult. I continued to work reflexively with this immediately after the interview, and have continued to do so. From this I am even more acutely aware of the impossibility of removing all researcher bias from human science research and of the richness that reflexivity can bring.

Continuing to radically reflect on this experience and immerse myself into the transcript and reimagine myself back in the interview, I was drawn to a section that I had previously overlooked. In this Julie said,

‘The staff here have the luxury of the time to get to know most of the people we care for, and that can only be a **good** thing.’

Gradually I began to see that Julie did value her shared caring role with others and that it was perhaps her belief that person-centred caring needed more time than was available to her in her position that stood in the way of her being able to achieve this. I wondered too if her managers were at least in part responsible for not facilitating the development of the person-centred workforce they promote.

### Corporeality

Some deeper understanding of Julie’s experience of person-centred care came when I began to look at the existential corporeality. To this point my attention had been drawn to Julie’s experience of time and her focus on tasks that needed to be done in time, to people, rather than any focus on relationships with people or of people as embodied. Being forced to consider corporeality drew my attention to other details concerning Julie’s own body and the bodies of people with dementia.

Because Julie appeared not to offer much in the interview directly related to corporeality, towards the end I asked her directly about the effect her work might have on her body. Initially I thought that her reply offered little insight into her experience of care, but with further reflection, I began to see more. Julie replied to my question saying,

‘It depends on the day, on what’s been going on - but normally I don’t feel **physically tired at all** –  
But I do feel **mentally** tired, especially if there has been an incident going on, because obviously –  
thinking, and re-thinking things –  
Could I have done something different? Or, have I done something

wrong?  
Or, did I do the right thing? -  
it can be a lot, **and I can never** switch off at work...  
If it's nice weather though, I can walk home and **that** does it,  
or when I get home, I can sit and watch the news and **then** I can get  
rid of it -  
the day I mean.'

Her emphasis on 'physically tired at all' was added to by her then quite long description of the mental tiredness she felt and her ways of dealing with this. I became aware that I had initially been making the mistake, as perhaps she was doing too, of somehow detaching her mental state and not seeing her as embodied. 'Julie' was tired by her work.

In the very final minutes of the interview I wanted to try and break through the remaining formality I still felt between us, so asked Julie to tell me about 'a thing that made her feel good, the very best part of her person-centred caring work'. To which she replied,

'The thing that makes me feel good...  
This might sound **completely and utterly ridiculous** but um - -  
One of the things that makes me feel good –  
it's just to see a smile on someone's face.'

To which I replied, 'I don't think that is ridiculous at all, I think that's lovely.'  
And inside I took a deep sigh of relief.

### The Essence of Person-Centred Care for Julie

Although Julie's care was practical and responsive and was delivered with considerable enthusiasm, I think it was missing many of the elements in the models and frameworks of person-centred care that I have presented in Chapter 3. Therefore, although her place of work promoted the care they offered as being person-centred, it seemed to be quite far from it. Her care was essentially time and task focussed work in which she needed to ensure the best use of her and other staff's time and skills for the smooth running of her work place, with the ultimate purpose, or in her words, her 'primary function' being 'managing people' who 'could not be managed elsewhere'.



### The Meaning of Person-Centred Care for Julie

From spending time with Julie's transcript and from the interview itself, I feel that person-centred care meant very little for Julie apart from the name of a model for care to which she was, by virtue of her employment, signed up. It seemed the enormity of her task-focussed role over-shadowed everything else for her. I got the sense of her being something like the synthesis of a queen and worker-bee or a queen and soldier ant, productive, efficient, consistent, strong and dedicated. I was sure she lived with an unspoken tension between the essence of her work each day and a desire for the 'luxury' of a different way of caring that she observed in others, but was unable to do herself. And, as with other participants, I wondered did she, but perhaps for different reasons, yearn for deeper I-Thou relationships and embodied-being-with others that might see more smiles in each day and less separation from the other staff so that the burden of each day could be the team's, rather than hers alone, with perhaps less to 'get rid of' at the end of each day.

### Participant 7: Linda

Linda was so strikingly different from Julie. She whirl-winded, or more like tornadoed into the interview, rather like Sally before her had done, and began talking about her work even before I had explained the interview process and before she had signed the consent form. I therefore felt like I was reining her in and pulling her back to do this, but she realised its need and once the task was completed she was off again.

Linda is relatively new to Jersey, referring to herself as a 'newbe'. She is in the process of completing a degree but has been a registered Mental Health Nurse for some time. She appeared to be extremely knowledgeable about what she called 'personal-centred care' and a champion for it, referring directly to this more than any other participant. Sadly however, most of the content of Linda's interview was a criticism of the practice and care she

witnessed where she worked, which she described as 'being in the dark ages' and did not compare favourably with places she had worked in the UK. When I asked her if she had shared her observations with any other colleagues she said she had not, firstly because she had not been offered the opportunity to do so and because there was no supervision or peer support groups. She then said that, because of her 'newbe' status, she felt she could not say anything for fear of being considered judgemental. I wondered therefore, if she sensed in me a 'compatriot' and felt safe and enabled to share in the way she did, moving seamlessly it seemed from one story, observation, scenario or criticism to another. As I spent time with her transcript I felt I was transported back into the room with Linda, aided almost certainly by her very strong regional accent, tuning me back into its music so easily. Although this relocation was relatively easy, I was surprised when I realised that I had made more notes while engaged in this reflection than with any of the other participants. I wondered whether these were an embryonic, un-actualized manuscript for her music from which I was beginning to see her as a heroine, a lone ranger riding in to save the islanders.

### Temporality

Time for Linda seemed to be categorised by looking back to previous jobs in the past where she believed that care was more person-centred, compared with the present, and of her vision for the future. She described the present as 'being in the dark ages' and continuing this theme said,

'You could get run down by a bus in UK,  
but here in **Jersey**, it will be 'orse and cart wont it –  
if you know what I mean.'

When I prompted her to say more she continued,

'I'm **trying** to tell 'em over here what I've seen in UK –  
and I get so cross when I see 'em trying to shove PRN in patients,  
because me, I'm a great believer in everyone should 'ave one-to-one  
– but it's all governed by funding, money, and...  
sorry - but you can have **all the research**, but - at end of day, it's  
down to money here.

They **have to** move with times.'

Based it seemed on her experience from the past and her present living experience, Linda had interesting plans for her future, and, as a result of the interview, it seemed for my future too! She said,

'I want to win lottery, and get my **own** care home - my **own** place and that.  
We'd have therapeutic fish,  
they'll eat better, old fashioned food – not lasagne and curry –  
and we'd have a nice bathroom with a screen –  
and ducks over mantle piece  
and a picture of the queen –  
and you could be Managing Director.'

When, not surprisingly, I questioned this position, Linda quite calmly and seriously, with no hint of humour at all said,

'Well we'll do more research then - and get ourselves sorted –  
and maybe you and I can get on Health Care Commission then -  
Then we won't have to keep our mouth's shut.'

This indicates Linda's tornado-ing stance very well - straight into action -no mincing of words. She seemed to have no time for this.

### Relationality

I sensed Linda was desperately lonely, maybe homesick, but more probably missing the sense of a shared identity with others who had her enthusiasm and experience of person-centred care. She seemed to be out of place and time and struggling to make sense of person-centred principles in a flawed context. The image of her as a lone ranger on a very lame horse was growing at this point and as I focussed on this I began to see that although its clarity was sharper, I had already glimpsed this faint image in the other participants' experiences and it was already known to me.

Linda told me of an experience that highlighted this saying,

'There was this lady who said to me  
"I'm sick of you doing all work for me on your own"

so I suggested she do breakfast with me.  
I looked at risks, but all she wanted to do was 'elp,  
and all I really wanted to do was 'elp her –  
**and** show others (staff) the way forward,  
but they were all "**oh, you shouldn't be doing that**".  
But I thought, well - **what's wrong with a tea pot** – it doesn't matter if  
she spills a bit,  
but I was on my own with that one...  
There is different nurses in this job –  
there's those that just want to do less with patients –  
and there's me who wants to do more.'

Although Linda's relationships appeared strained with her colleagues, maybe because she had these seeds for change, but was lacking the skills and means to implement these, she nevertheless spent much of the interview talking about the people for whom she cared with obvious delight in her voice. She seemed to know them well and spoke of her emotional attachment to some saying,

'Now some of nurses find it hard to deal with dying –  
but no matter - with this age group - you get attached.  
I know in training they say you shouldn't get emotionally attached –  
**but you've got to** with patient, and family need to see it...  
And it's **got to come** - you can choose your friends but not your  
nurse or carer.  
You are the one they have to come to...  
and I like to think that if I was here, and nobody came to visit me,  
somebody would give **me** a hug -  
so I always go around and I give them a hug...  
but '**other half**' will probably say to you, "**oh you shouldn't be doing that**" –  
but I'm a great believer in being warm.'

I have included this section from Linda's interview because of the clear tension evident between her training that taught her not get attached to patients and her experience of this as natural and necessary in practice.

## Mood

I'm sure that the aloneness that Linda seemed to be expressing must have affected her mood, although she did seem surprisingly buoyant, frequently using the words 'chivvying along' which she enhanced with dance moves in

the interview, to describe her caring role. I wondered if this was as therapeutic for her as for the people for whom she cared. I wondered too if her apparent buoyancy was something to do with the relief I sensed she was feeling at being able to talk in such detail and having someone to listen to all that was so clearly on her mind and needed saying. As I write now, sometime after the interview, I am wondering if, as with so many other nurses recruited from the UK, Linda may perhaps have already left Jersey and returned home, such was her apparent disappointment with her work situation here.

### Spatiality, Materiality and Corporeality

I have included these three existentials together because so often these seemed intricately intertwined in Linda's descriptions and that any attempt to separate them would require such fine surgical skills that I thought any slight slip of the knife could potentially lead to significant trauma to the descriptions. One clear example of this was when Linda was talking about the day room in which most people spent most of the time. She said,

'And I feel, **how would you like to be sat in a room with people you don't know and don't want to be sat with!**  
There should be more **personal** spaces...  
and in **my** care home there would be **proper** personal-centred care.  
You talk about it here - but it's governed by routines and it's like a hospital –  
and because of this you have institutional behaviour.  
There's nothing for them to **do**.  
In UK we got a post-box and two little dogs (*which I later realised were toy dogs*) and one man kept wanting me to give him food to feed his dog.  
So - I got money from King's Fund and went to ELC and got some plastic food – lettuce and tomatoes and buns and he fed the dogs these,  
and he never said "Dogs don't eat this stuff"  
but after that he was so relaxed and **happy** and never kicked off.'

Later on she described the time when she herself felt so bored and stressed from doing nothing in the dayroom that she instigated Tai Chi sessions. She said,

'When I first came here I bought Tai Chi,  
and they (*staff*) looked at me and said "**What are you doing?**"  
I said to them "Patients must be **bloody bored** because **I am sitting here.**"

So I went "**Come on**, we are going to do Tai Chi!"  
and I said "5 to here, and 5 to there" (*Linda did some actions*) but  
staff were all like that (*Linda pulled a sour looking face*) and I said  
"This one is good for the shoulders, and you'll get all pain off top of  
your 'ead" because with **this** job you get it.  
But people look at me and think...'

From this part of the interview Linda's frustration with her colleagues and the system was palpable, being very evident in her body and speech. There were many more such examples but one I think brings these existentials together so powerfully and reflects Linda's loquacious style so well, was her anecdote concerning the 1812 overture. This followed on almost immediately from the Tai Chi scenario above. She said,

'When you're in toilet and you've got someone in there having a wee –  
**or** something else –  
In the bathroom there isn't a screen you can hide behind, like in UK –  
so **how** do you 'elp that patient relax?  
You could say nothing - but 'it' can be heard int pan.  
So what do you do? -  
1812 overture comes in handy. I find **that** works.  
It's all that I've learnt.'

### The Essence of Person-Centred Care for Linda

Linda was adamant in her belief that some people were just born carers, and she herself was very specific about the essence of person-centred care, which from her descriptions, she certainly aimed to deliver. She said,

'The caring were **in** me. It were embedded in me... and I think **you've got to 'ave a passion for elderly** - and it's **got to** come from within you.  
Some people '**ave it** and some people **don't** 'ave it.  
And the '**it**' they '**ave to 'ave**, is – it's - being a carer, a nurse, care co-ordinator, and entertainer, singer, dancer, eye-watcher and risk taker, **you've got to be** strong - able to de-escalate things, make 'em laugh and let 'em cry, make 'em **enjoy** the life they've got.'

From this list it still appears that Linda was predominantly task-focussed in her caring and that, although she was practical, responsive, supportive, relational, compassionate, respectful, embodying person-centre values, the limitations of the macro context, the care environment and person-centre processes restrained her.

### The Meaning of Person-Centred Care for Linda

Although Linda was so passionate about person-centred care and I believe tried so hard to deliver this as best she could in the context in which she worked, from spending time deeply immersed in her experience through the transcript, the impression of her being 'caged in' began to grow. Resting with this, I recalled this phrase from a poem by Maya Angelou 'his wings are clipped and his feet are tied' which led me to re-read her poem *Caged Bird*. Although Angelou wrote this as a creative response to a very different situation, I nevertheless could see how much it reflected so perfectly what I had interpreted as the meaning of person-centred care for Linda. For this reason I have included this poem in the appendices with the expectation that, without my interpretation of it, it will bring you closer to what I understand to be the meaning of person-centred care for Linda - a caged bird with clipped wings and tied feet (Appendix H).

### End Reflection: Linda

I was left wondering how Linda could keep silent for so long, apart from speaking with me, seeming so convinced that what she was witnessing was not good person-centred care and that this could be done better. Resting with this thought and developing it reflexively and into some deeper radical reflection (Merleau-Ponty, 1945/1962, 1964/1968) I found I was in the centre of this (Ibid. 1964/1968 p. 139). I wondered if I was considering something of my own story and actually some countertransference was bringing me some new insight. Linda's experience echoed in my soul, bringing to mind times when I had seen care that I knew fell short of best practice and which, at the time, I felt powerless to change. I remembered the *Thinking At The Edge*

session I referred to briefly in Chapter 2 in which I felt challenged to 'shake up the system' and 'advocate' for people with dementia. I wondered why Linda was not doing this. I wondered was I being challenged in this 'reflexive dance' with Linda (Finlay, 2011 p. 81).

### Participant 8: Katherine

Because I had known Katherine for some time and had occasionally worked alongside her, I did not initially want to include her as a participant in this research, thinking that what I might already know of her from my own observation, might seep into and swamp the new data from this research. This I thought might prevent me from hearing a new song, and that if she spoke only in whispers, my pre-knowledge might deafen me to these. However, after having completed all the other interviews and much of the data analysis for these, I became aware that it was very likely Katherine's experience of person-centred dementia care could bring some new insight to this research, so I therefore included her as an eighth participant, listening all the more attentively to this new data.

Although not initially from Jersey, Katherine has worked here for many years and considers this her home. She began her nursing training immediately after leaving school at a time when person-centred care was not included in the curriculum. Reflecting on this she said,

'If you could see what I saw then, you would be **horrified** – and the ward was called, 'the back ward' because they didn't know what to do with the people who filled it.'

Katherine then described some of the regimes and practices in place, saying of these,

'I knew it was all wrong - but I was so young - and I couldn't say anything. I thought then - **Is this it?** - Is this what happens? It was **horrendous**.'



I have included Katherine's reflection on her past in this introduction because I feel that it has been some of the inspiration behind much of what she has done in her professional life since then. This has included attending courses in person-centred theory and care in the UK, promoting training in this in Jersey, and her work now as part of a team of various health care professionals caring for people with dementia in which she aspires to practice this person-centred care.

### Mood, Corporeality and Relationality

Katherine, like some other participants, seemed eager to begin the interview and, almost immediately, started to tell me about a meeting she had that day with an 'elderly gentleman with dementia' who she initially considered was not really engaging in the conversation she was having with him and his wife. She described him as 'this **poor** man' and told me that he had just returned from hospital in London where he had a procedure on his heart, and that he was 'in quite a state and black and blue' because he had also had a fall. She said,

'He sat there, not really joining in or asking questions, but all he could say from this really was that - he had vascular dementia, heart problems and had a fall. I was talking to him, and I was stroking his back, and I said, "I really hope you feel better soon" - and he said, "I've just had a stroke." Well at first I thought, oh dear, he's not understood this, and then I caught his eye, and I knew he meant me **stoking his back!** So I laughed with him and then he said, "You have such a big heart" and I said, "Oh, thank you for that." And he then laughed some more and pointed to my jumper and said, "**No, on your jumper**" - which had a heart pattern woven into it, and I just laughed all the more. He was **really, really funny**, and I thought - Oh - you can make assumptions about people... I was seeing this little old man - with these physical problems - and this diagnosis -

but he wasn't in as bad a place as I thought.' (*Katherine laughed as she retold this story.*)

It was lovely for me to be brought into this experience in this way and to laugh so much with Katherine. I think this helped break the researcher-participant ice between us and set us back in our more usual frame of relating with each other. It also showed me something more of what I knew of Katherine's big caring heart, which this person had more than glimpsed in their meeting together. From this scenario I could see that Katherine was able to tune into his mood and join him in it and there was obviously warmth in the relationship between them, through not only her gentle touch, but her laughter and words as well.

As the interview continued, it filled up with other examples and stories Katherine told about her patients which wove corporeality, mood and relationality together so seamlessly, sometimes also including references to spatiality and materiality.

#### **Spatiality, Materiality, Mood, Relationality and Corporeality**

After a brief pause in which Katherine sat quietly smiling, as though reliving the experience I have described above, she continued speaking, temporarily changing her focus to share her reflections on the place where she worked. Within a few seconds however, she was once again incorporating so intricately, all the existentials above. She said,

'What I was thinking about is where I work -  
I think that we are lucky there because we can access different spaces but until now I hadn't really realised the extent to which I do this –  
you do it unconsciously.  
People going there can be anxious, especially for the first time, so we try to make it as comfortable as possible.  
Sometimes it can be a bit busy and noisy there,  
so I may ask them to wait somewhere where it's a bit quieter –  
you can do it, without almost thinking -  
you just look at the situation and the person - and do what you think is best.'

When I asked her to give me an example of this, she was immediately able to tell me about another situation that had arisen that day. She continued,

‘When I saw this person coming in, he took a long time to get from the door to the chair –  
and I realised he must have already had a long walk from his car –  
people don’t realize they can just pull up outside –  
so I quickly found another room that was free, and nearer where he was sitting -  
so we used that, and found him a higher chair which was easier for him to get in and out of.  
So I guess - I do weigh things up for the person and do my best for them –  
and don’t take it for granted that people can get from one room to another as well as me.  
He was just walking **so** slowly and it looked painful.’

I listened to the recording again after transcribing the text because I was immediately aware that there were far fewer bold typed words in this transcript than with any other participants. I am aware that there is always a gentleness about Katherine, but I wanted to be sure I was not missing any subtleties in her speech. I wondered too if the times when we had laughed together had disguised these. Listening again I heard her gentleness above all. She was so at ease as she talked to me and I could sense by the way she spoke about the people for whom she cared that she was relating to them as easily as she did me. When I asked her to tell me more about how working so much with older people with dementia, other illnesses and disabilities made her feel, she surprised me by saying,

‘Oh it makes me feel **young**!  
**I am** stronger and younger than them - I want to put them at their ease and do all that I can to help –  
so I’ll move the furniture because I can -  
But it’s not so much what you do or what you say –  
it’s what you can do to make them feel better...  
So - I find out what is important to them...  
a professionalism that allows you to leave yourself out - as much as possible - and concentrate on them.’

These scenarios seemed to me to be so person-focussed and as I reflected on the image of Katherine 'feeling young' I began to craft the following short poem. I have called it *Moving Mountains*.

### Moving Mountains

Looking at your time-tired body  
Headed by feathery, life-worn brain  
Makes me feel young and agile,  
Able to move mountains,  
Make a plain.  
So whether it's a distance that's just too far,  
A seat that seems too low,  
A kindly word needing to be spoken,  
Or a touch to calm your soul,  
I am here  
Near  
For you.

### Corporeality, Mood, Spatiality, Temporality, Materiality and Relationality

There was little doubt in my mind that Katherine seemed dedicated to the task of putting herself in the others' shoes, a phase she frequently used to explain why she did what she did, saying it enabled her to hear, and then empathise with others and constructively meet their needs. She said,

'I do try... I want to put them at their ease,  
get in their shoes and see their point of view...  
and we've made an effort in the consulting room, to make it nice and comfortable, and the picture we chose as a thing to help conversations.  
And I try to make my body language say that I want to be there for them, even though my mood is like the tide sometimes.  
But when you've got bad news to tell them –  
you need to tap into that empathy,  
and if you can see they are struggling,  
you give them some water, pass the tissues.  
It's just to say we are listening - and we see your distress.'

Katherine did not always find her person-centred work as easy and rewarding as it seems from these descriptions above. She also spoke about how difficult it was giving people bad news and when trying to decide whether or not to attempt to re-orientate people to her reality who seemed to

be in different times and places to her. Others' limited training and the ineffectiveness of much of this also seemed to dampen her experience of person-centred care in Jersey. About giving bad news to people she said,

'When I have to tell someone they can't drive any more, that **breaks my heart**.

Driving may be their only way of getting out and about, and to tell them they can't do that, it's **so sad**...

We can be more upset than them –

it can be so emotionally draining sometimes.

It's **their** attitude to the news which upsets me - and I had not really thought about this till we started talking –

but I guess it's empathy.

And some **really** tug at my heart-strings because sometimes - sometimes, I haven't got the solution - so you can't help people – and that is difficult - you just have to reassure people.

That's difficult - - -.'

Katherine was visibly heavy-hearted as she talked, a sadness she drew me into so easily, perhaps because of her genuine passion to care, but also I think because she was speaking about something of my experience too. When I have been unable to help people find the solutions they needed, and all I have been able to offer has been the reassurance of my presence, I have sometimes felt disheartened.

It was then, when I asked her to talk about other difficulties she encountered, that Katherine began to talk about how hard she found it when people she cared for experienced other realities to hers saying,

'I know you are not **supposed** to confront people with your reality – but to meet them in theirs – that's the theory,

but that's not that easy when you have my job to do.

Like with Dr Baxter -

it's the **reality** of my job that has to dominate - even though the theory says something other.

That makes it hard - and it's even harder because you **should** encourage their personalities out, and not see them all alike as 'patients' -

but it's sometimes hard to do this.'

Katherine continued telling me about Dr Baxter who had been a consultant until fairly recently, and then of other people much like him who seemed to be living in different times and places and reliving past experiences. In response to her experience with him and the other people she cared for with dementia I wrote, *Who, Where, When?*

Who, Where, When?

Earlier on he was Dr Baxter again  
Attending to all his patients,  
All diligence of duty,  
White coated, I expect,  
With pocketed stethoscope, no doubt.  
But just now he's exhausted  
By a long day's labour?  
So he sits amongst them,  
His patients,  
In their waiting room,  
On vinyl covered chairs,  
United by diagnoses  
And merging identities.

So now I must wonder  
As the one at the helm,  
If it's kinder to be the re-minder,  
To encourage more rest,  
To distract from his labour,  
Help put his mind at rest?  
Or should I encourage his toil,  
Be his colleague for a while,  
Continue his misconception,  
And join Dr Baxter on his rounds?

There was a natural pause following Katherine's description of her experience with Dr Baxter and sensing some tension between the theory she certainly knew very well and these problems in its application, I asked her if she thought other staff met similar challenges. She then told me about another member of staff whom she described as, 'fantastic' because he so easily 'linked into what was right for them (people with dementia) at the time'. Katherine then continued to talk more about her colleagues and other health care professionals working with people with dementia in Jersey, following her own link to training. She continued,

‘Sometimes people like Jim don’t have to have any training in person-centredness, they just **‘are’** it - without the training. And I think some things just can’t be taught - but I’m not saying there’s no place for it – there really is a place for thinking and reflecting on what it might be like for a person with dementia, like reflective practice – but we don’t have that here really - it would be a bit of a luxury. It **would** be really good because it helps staff to feel they are all singing from the same hymn sheet - but management now – they don’t encourage relationships between staff, and staff and patients - they just see people as jobs to be done, that need doing – but I don’t see it like that - so there are challenges.’

This last section seemed to tumble out of Katherine, as though this was perhaps what she really wanted to talk about and what really fired her up the most. She seemed to be longing for a chance to be more person-centred in her work and for this to be facilitated by her managers with opportunities given to engage in more reflective practice, yet she also seemed to be saying that some of her colleagues ‘had’ it without this.

### The Essence of Person-Centred Care for Katherine

From the descriptions Katherine shared in her interview, it was clear that person-centred theory added some structure to her practice and attended her caring, and that this had been so for many years. Although she was unaware of any models or frameworks for practice, she appeared to seek out as many opportunities as possible to care in this way, often opting to work independently, or initiating new activities or services to promote this. Person-centred care for her was essentially a theory she attached to her embodied, heart-led, compassionate, empathic response to an Other in a system that seemed to pull her in another direction, focussed on a person’s symptoms of dementia.

### The Meaning of Person-Centred Care for Katherine

As I spent time reflecting on Katherine’s lived experience I felt a peacefulness and strength in the scenarios. This was like the confluence of

two gently-flowing streams merging into one effective river which I interpreted as the meeting place of her care and her life philosophy. It seemed she approached her work in a peaceful way, knowing she was able to reposition herself when situations conflicted with her beliefs in how things should be done. This meant that she could be moved with compassion by the Face of an Other, accept their alterity (Lévinas, 1961/1969 p. 194) and able to allow I-Thou relationships (Buber, 1937/1953) to be breathed into being. In all her gentleness however and with such generosity in her relationships, I nevertheless also saw her as a defender, an activist and a crusader in her difficult working situation.

### End Reflection: Katherine

I found it necessary, following on from my deep immersion into Katherine's lived experience of person-centred care, to take some space and time for radical reflection on this experience. I felt quite overwhelmed, not only by the enormity of the task, but also by the responsibility and need to get this right. This was undoubtedly because I knew Katherine better than any of the other participants, our paths crossing occasionally in our different roles, but also for some other reason that initially was not so clear to me, but was nevertheless clearly there in its shadows. In such shadowy situations in my counselling work, and more recently throughout this research, I have trusted the process of *Focussing* to bring enlightenment from my 'speaking' body (Gendlin, 1978/1981). Applying this I moved from a felt sense of being 'small', but in the presence of something 'bigger', to the word 'esteem'. Staying with this I began to see that I had Katherine on some sort of pedestal and that it was my judgement of what constituted good care that had put her there. Alongside her was Jean Vanier (1928-) to whom I referred in Chapter 2 because of what I also considered his exceptional care. I saw them as related as carers and by my liking of them.

I have shared the outcome of this radical reflection and my reflexive consideration here, because I am aware that my opinions have been formed from witnessing their care for others, and this will have influenced my



interpretation of Katherine's data. I approached this analysis having well-sung songs for both Katherine and Jean that I hope you will be able to filter out to come closer to Katherine's experience of person-centred care, without my voice influencing her new song too much.

## Stage 2: Focussing on the Existentials

'They (continental philosophers such as Sartre, Heidegger and Merleau-Ponty) argue that we all have an *embodied sense of self* which is always *in relation to others*, while our consciousness is shared with others through *language, discourse, culture and history*. We experience *time* in our recollection of past joys and trauma. We also anticipate what is to come in the future. We are placed into a matrix of *spatial relations* in the world surrounded by things which have *meaning* while we engage with ideas and activities which become our *projects*.' (Finlay, 2011 p. 19 Finlay's italics)

'Mood, in some way, saturates our being-in-the-world and is just as primary as spatiality, temporality, intersubjectivity and embodiment... It is a powerful messenger of the meaning of our situation.'  
(Galvin and Todres, 2013 p. 29).

As this stage loomed ahead of me, I became increasingly aware of the complexity of the challenge I had set myself, so constructed Diagram 3 (p. 165) to summarise my three stages of analysis. The task however remained complex and onerous.

While the existential nature of this research began with the individual participants' experiences of person-centred dementia care, I also considered there may be additional insights available, but latent and potentially not uncovered by the initial focus on the eight participants. By slightly and subtly shifting the focus towards the six existentials within their transcripts, I hoped to discover more from each participant, before drawing this all up, or 'pulling it all together' (Finlay, 2011 p. 248) still further in stage 3 into summary essences and meanings. Such phenomenological generalisations are not intended to stand alongside empirical or quantitative generalisations, derived for the purpose of drawing conclusions or establishing new factual

information, but instead my phenomenological merging of data follows van Manen's call to "never generalize" (van Manen, 2014 p. 352). This maintains and respects the singularity and uniqueness of the participants' data, which in phenomenological inquiries, can be achieved by orientating towards eidetic or essential understandings, that is, what is universal or essential about the phenomenon, as uncovered through the participants lived experiences. Todres also encourages phenomenologists to 'stay(ing) close to the unique individual' not only for the immediate richness this offers, but also because by so doing other 'social' and 'universal significance' may also to be found beyond this (Todres, 2007 p. 8). However, like van Manen, he too cautions against efforts to generalize because of the potential this has of aesthetic texture being lost in the process.

With such caution in mind, what follows now are six short reflections arising from this shift in focus towards the existentials. I worked through each existential in turn, returning to all the participants' worked data above and immersed myself in it all once again. From this immersion I crafted these reflections. Following this, as discussed in Chapter 6, I have also incorporated a short section in which I give some attention to the 'background' left in the transcripts once the 'figure' of the existentials had been considered (Iser, 1980 p. 94-95).

### First Existential – Spatiality

It was interesting to note that all the participants, apart from Monica, made frequent references to the space in which they worked, though with varying degrees of emphasis. These references were almost entirely negative, apart from some of Sally's and Katherine's experiences, with each negative experience focussed on the way in which the physical environment directly affected their ability to care and the negative affect these spaces had on the people for whom they cared, such effects also documented by Tonuma and Wimbolt (2000), McCormack (2001) and McCormack and McCance (2010 pp. 84-87). Negative experiences of space included: a sense of being 'locked into' the care environment, of being devalued by the poor quality of the work

environment, but not defeated by it, of battling to get other staff to respect the private space of the people for whom they cared, inflexibility in the use of space, including confinement in day rooms and locked bedrooms in the day; and forced company with other staff and between people with dementia because of this confinement in one area for long periods of time.

Direct references were made to these spaces being either home/homely or not home/homely, ideas I was perhaps more able to hear as loudly delivered songs having read papers by Galvin and Todres (2011, pp. 3-4; 2013, pp. 71-72) based on Heidegger's ideas (1927/2010) and Zingmark (2000) on this subject. From my reflection on these descriptions, it seemed it was most participants' intention, apart from perhaps Julie's, to make the environments in which they worked as homely, comfortable and welcoming as possible. While I believe the participants felt some sense of heavy responsibility for this, it was clear that they also felt limited in their ability to affect them. There was also some sense that the space was dominated by the routines that took place in them.

As I reflected more on the spaces described by the participants and thought about their locations, all of which were well known to me, and of the history of dementia care in Jersey, and of the limited training in person-centred care available here, and of how far from ideal the participants considered these spaces to be for person-centred care, I was struck by a feeling of their shadowiness. I stayed with this feeling and from it came a sense of these spaces being 'in the shadow of the asylum'. I wondered if this thought had taken hold of me because some of the care environments are literally in the shadows of the old, now mostly unused asylum. With further radical reflection its metaphorical significance loomed up and staying with this idea I began to craft *In The Shadow Of The Asylum*.

### In The Shadow Of The Asylum

Shadows hold onto their secrets  
Mixing up the colours of our landscape

To uncertain shades,  
With ghostly, shifting movements  
And unpredictable, distorted sounds,  
Dampened and dulled down  
By the moss growing deeply there.  
So, would we even know  
In all this our confusion,  
Through this grey-green hue,  
Of any life, or form, or colour,  
Nascent, emergent, rising,  
And bringing something new?

### Second Existential - Corporeality

Most participants made many references to the bodies of the people for whom they cared and seemed to understand their personhood as embodied, in that caring for the body meant caring for the person. Although such caring seemed to be initiated by care plans designed by nurses who were not immediately engaged in the day-to-day care of people with dementia, as described by Julie, most nevertheless spoke of these activities empathically. It seemed that having some idea of how they themselves might feel in such circumstances helped them to identify with others' needs and contributed to their 'attentive being with' that Post (1995 p. 3) described. This however often eluded them and was not always as evident as the participants would have liked. I also sensed that although embodiment was an acceptable idea, their relating still seemed mostly corporeal-centred rather than person-centred. Perhaps in accepting the idea of embodiment, their focus may have shifted too far towards the body to become more about managing others' bodies.

The issue of boundaries was never too far away either with differences of opinion about the positioning of these with some participants feeling judged by other colleagues. Some kept clear, high boundaries in their person-centred care, while others, like Sally wanted such walls to be as low as possible so she could 'put her whole self in'. However, I sensed with all the participants that these did have a restraining function in corporeality.

I was also aware that participants spoke both of their own bodies and of those for whom they cared, with some implicit sense and some explicit detail of a shared identity of owning an ageing, tired or less than healthy body. Although I am accustomed to such personal disclosure in a counselling context, I was quite surprised at the extent of this sharing in this research context. From this I intuited something of the importance of the effect that feeling old, tired, achy or stressed had on their capacity to care. Although often occupied by their own bodies in this way, most participants seemed able to feel beyond their own bodies, with Linda being resourceful enough to 'chivvy others along' no matter what, and look beyond the exterior presentation of others' bodies towards the embodied person, showing remarkably little aversion to the practical, personal care aspect of their work.

### Third Existential - Temporality

From the participants' experiences it was evident that they, as Finlay suggested, experienced time in recollection of the past, consideration of the present, and of the future (Finlay, 2011 p. 45). All described poor caring they had witnessed in the past, and expressed hopes for a future in which caring would be better than the present. Most also seemed to consider time for people with dementia in terms of the past, present and future, which seemed to be defined mostly in terms of decline. This association was strong and seemed to make people's existential time seem heavy as participants shared their experiences. From this and further reflection, I got the sense that, despite their best efforts to care, participants believed that people with dementia were not living as well in the present as they might and were seeing the future almost before it arrived in their declining bodies. These images seemed so sad and carried an unspoken, though I believe implicit, 'why and for what purpose?' questioning. These images and the image of the waiting room in Katherine's portrait played in my mind and merged with Arthur's story in Sally's portrait, from which I wrote *They Shall Not Grow Old*.

### They Shall Not Grow Old

They shall not grow old  
As these who are left  
Grow old, contained, alive,  
In waiting rooms of decline.

They shall not grow old  
Those heroic men at rest  
Young bodies safe beneath  
Red carpeted fields of war.

They shall not grow old  
Saved from this bloody war.  
Bullets and land mines survived  
For steady retreat and in-action.

A second image that caught my attention was one of a runner running a race without a finishing line. This spoke of something unattainable or futile which derived from the participants speaking of attempting to practice person-centred care but just never having enough time to be person-centred. This included participants voicing the experience that meeting the requirements of care plans and paperwork, of literally organising patients' time and being directed by time plans, usually took precedence over time for *being* person-centred (Sheard, 2008) and for open-heartedness (Galvin and Todres, 2013 p. 177). This was voiced alongside the experience of being short-staffed and the need therefore to do the same tasks in fewer staff hours.

Most participants also talked of their need to be flexible in their understanding of time and shared experiences where the people for whom they cared were experiencing other time realities to themselves. While this demanded compassion and intuitive, investigatory skills in which they often felt unskilled, I also got the sense that this was not onerous and sometimes offered a place for humour and opportunities to express their deep care and concern.

A final and significant aspect of temporality, first voiced by Jane, and which lingered throughout my dwelling with the data, was the sense that the participants were time-tired and concerned that they would not be able to find the stamina or endurance needed in their present positions until they reached retirement age. Their stamina however seemed to be boosted by their hope that there would be positive changes ahead with the proposed reorganisations within health and social care in Jersey, which would make person-centred care more feasible.

#### Fourth Existential - Mood

I had not initially considered incorporating any existentials other than those described in van Manen's earlier literature (van Manen, 1997, 2002) and in other phenomenological research I had read (Bland, 1999; Moene and Bergbom, 2006; Eggenberger and Nelms, 2007; Dewing, 2011) until I became aware that van Manen himself had proposed a fifth existential of materiality (van Manen, 2014). I included this because of its significant potential and then looked for other such helpful lenses. From this search I found that Galvin and Todres had begun to include mood as a further existential saying that it,

‘saturates our being-in-the-world and is just as primary as spatiality, temporality, intersubjectivity (relationality) and embodiment’ (Galvin and Todres, 2013 p. 29).

With this endorsement, I included it and found it to be insightful, particularly when I began using mood interchangeably with emotion, finding that the implicit tensions I had felt earlier began to be named.

The participants' descriptions of their lived experiences then seemed loaded up with mood and emotion, the most pervasive, in all portraits, being that of disappointment, particularly so for Linda. This seeped into and 'saturated' peoples' experience of caring primarily because they were not often able to practice their caring as they thought they should and was incongruent with their beliefs and values concerning the nature of good care. They were

restricted by time, understaffing, poor quality environments, professional boundaries, distant managers and the perceived judgements of their colleagues. I sensed that the feelings associated with this were deeply embedded into them and never vented out through supervision or peer support groups. There seemed, from my reflection on this, that there was sometimes confusion in what they thought they ought to do and difficulty in prioritising aspects of care. Disappointment then seemed to give rise to frustration and real sadness that the heartfelt empathy most seemed to be expressing could not be translated into increased wellbeing for the people for whom they cared. The idea of 'compassion, stretched to its limits, (is) going numb' (Sontag, p. 97 in Banner, 2014 p. 99) seemed to fit well here. Some said they felt angry because of this and others stressed, but most used the word 'hard' to describe their experience in such a way that this word too was loaded with mooded disappointment and darkness.

Further anxiety seemed to be present in the tensions expressed by the uncertainty some participants felt that they might not survive long enough in their work for it to become a life-long career and then, whether it was a job, 'a life' or a vocation. This fear of not surviving 'the test of time' was no doubt fuelled by all of the above aspects of mood, and I wonder too if others' negativity and the sadness of the situations of the people for whom they cared may have added to this.

Loneliness too seemed real, primarily because of the difficulties participants sometimes met in developing relationships with people with dementia with whom they spent most of their working time. They also expressed feeling distance and detachment from their colleagues because of the differences in their understanding of person-centred care, and with other colleagues not 'getting it'.

Over all this heavily mooded experience that seemed to weigh participants down, I could sense pride rising. Participants seemed proud of their work in



spite of the negativity they described and I imagine this must have been doing its restorative work in some way.

#### Fifth Existential – Relationality

The data concerning relationality fell into two main categories, the first concerning the participants' experience of relationships with people with dementia, and the second with other colleagues, but these were so intricately intertwined that it was sometimes impossible see them as separate.

Interestingly, I began to see that the participants' scenarios concerning relationships with the people for whom they cared fell broadly into two categories with some, like Sally and Katherine, wanting to foster close, friendly and meaningful relationships, prioritising a sense of 'being with' people with dementia, and others, including Julie and Katie, wanting to maintain distance as a priority in the relationships they had. They strove not for closeness, friendliness or tenderness, but considered good person-centred care to be more distant and thus more professional. I was aware that these two positions were taken quite confidently by both groups, and as a result of this, there were tensions between the two. It seemed that most participants had to champion their own causes and fly their own flags for their positions, because there was little leadership directing the nature of care, insufficient training or good examples of person-centred care to emulate, there was no mentoring, nor forums in which to voice their opinions or have them challenged. It seemed that those who were champions for, or more naturally related to people in I-Thou relationships, (Buber, 1937/1953) felt the pressure from other staff whose priority was the tasks that needed to be completed and that those who prioritised the care tasks struggled to make person-centred care a reality.

Both groups however found relating to people with dementia difficult at times because of people's limited verbal communication, often compounded by feelings of separation from them when it seemed they inhabited different worlds. Because of this I sensed a feeling of some 'individual togetherness'

amongst the participants. Some also expressed the need to protect themselves against the sadness they would feel when a person died or from unintentionally hurtful comments. Most however eluded to, or spoke specifically about how difficult caring was when their caring seemed one-sided and people with dementia seemed unresponsive. I sensed from this that person-centred care seemed unnatural to them and unlike other relationships that they maintained by both giving and receiving. While Monica shared a sense of being lightened by 'reaching out' I felt that most participants experienced a sense of feeling closed out by people with dementia. Dwelling with these ideas I wrote *I Reach Out*.

### I Reach Out

I reach out to touch you,  
Not like a lover,  
Or mother, holding,  
Hoping, and longing for  
Love's return.  
But for you,  
Arm wrapped around,  
And sterile gloved hands  
Tell you that I care,  
Waiting for  
Companionship  
With you.

I reach out to you,  
Your old hands  
Cold in mine,  
Unresponsive as though  
Buried already beneath  
The earth of time's ageing.  
But, I will return,  
To hold you again,  
Keep on holding you  
In your cocoon  
Of spider-webbing  
Wilderness,  
Barricaded  
Against me.

Not only did the participants describe relationality in terms of their relationships with people with dementia and their colleagues, they also alluded to, and occasionally made specific reference to, distant relationships they had with senior managers and service directors. I sensed that these were perceived not so much as directive but dictatorial, putting much of the blame for problems in the delivery of their person-centred care upon poor understanding, resourcing and management. In this there seemed to be some unity amongst the participants.

#### Sixth Existential - Materiality

As with the other existentials, materiality featured in all the participants' portraits. Most attention however was given to those things which assisted the participants' caring, or were part of their practice, rather than those of direct importance to the people for whom they cared. Only brief references were made to these, with all but Sally alluding to the absence of things in the care environments for the participants to do, or the absence of personal space to keep personal possessions. Linda described her fight with managers for interior decorations to create the homely feeling she thought was lacking and to provide other comforting activities. Sam spoke with obvious pride about the success of the picture book she had made for someone in her care and Jane battled another member of staff for the continual reinstatement of Mrs Giles' teeth. Their person-centredness was clearly evident in their concern for the people for whom they cared and this focus on material things.

While Sally's experience of her workplace was of it being comforting and homely, she certainly expressed very different ideas about uniforms. Because she believed these defined places as clinical and therefore un-homely they were not worn where she worked, though she did seem to have to battle for this with another member of staff who thought quite differently, her graphic description of this inspiring me to write *Badges of Flesh and Bone*. Others however, including Katie, described their uniforms in fine detail and the importance of them in their work-places which seemed to be very

defining features of their person-centred caring, helping people with dementia to understand who were the staff and their differing roles.

Most other references to materiality were either concerning the reams of paperwork which went with their jobs, and the associated care plans and staffing rotas, or of the poor quality equipment they used in caring for people, or that they did not actually have but would benefit from in their caring work.

### The Background Beyond the Existentials

Reading *The Act Of Reading* (Iser, 1980 pp. 93-94) first alerted me to the idea of foreground and background in a text, which Iser explained by using the example of Rubin's figure-vase, a two-dimensional form that can be viewed either as a vase or as two people in profile. This highlighted the possibility that after the existential detail from the transcripts had been attended to, there could be other material, which in the case of my transcripts would be the parts uncovered by my coloured highlighters, which may be important.

Going back to the transcripts there were indeed uncovered sections. Many of these related directly to the participants' family lives prior to beginning their nursing careers. All made reference to the examples their parents or other family members had been of excellent caring, either as professionals, or in community contexts where they grew up. As all included such detail, I wondered if this was significant in directing them towards their caring professions, the type of caring work and the standards to which they aspired, and was perhaps more significance for them than their mostly limited person-centred theoretical knowledge.

Many participants referred to their nursing education and the absence or insufficiency of its person-centred content, and although I have referred to this in some of the existential summaries above there were other parts which seemed to stand alone. I believe this is significant and I have returned to this in Chapter 8.

The participants also spoke about the activities and tasks in which they were engaged and, depending on their focus, I have included these in some of the summary existentials. However, it did occur to me that this category could form a seventh existential when describing the lived experiences of other phenomena.

Finally every participant spoke about the sense of relief and gratitude they felt at having been given the opportunity to talk about their work. I was very aware throughout the interviews that all, apart from perhaps Sam, spoke easily and with little guidance or interruption from me. It was clear they wanted to talk and I have also returned to this observation in Chapter 8.

### Stage 3: Summary Essence and Meaning

#### Summary Essence

In this section I have returned to the participants' experiences of their person-centred dementia care to provide a summary of the essential nature of person-centred care, its 'whatness', the 'thingness of the thing', and by so doing come to its identity (van Manen, 2014 p. 52). Here again I have engaged hermeneutically with the participants' texts, retaining their presence here too, but adding my voice with theirs for our co-creation of essences and meanings.

I am sure that many reading this thesis are doing so because of some interest in person-centred care and could therefore recognise it in practice and in literature, rather like you or I could recognise a table. Merleau-Ponty, using the example of a table, suggests that to find its essence, one needs to go beyond the factual descriptions to the experience of using a table (Merleau-Ponty, 1948/2008 p. 70). Likewise, I needed to know about the experience of person-centred dementia care to discover its essence. So this research has been a project of lived experience following Merleau-Ponty's

philosophy that 'In order to perceive things, we need to live them' (Merleau-Ponty, 1945/1962 p. 325). From careful attention to all the participants' descriptions of their lived experience through the lenses of the lifeworld existentials, and by 'stepping back' and being 'selective' (Finlay, 2011 p. 248) but holding onto what also seemed more 'universal' (Heidegger, 1971/1975 p. 189) the following have emerged as the nine essential features which constitute the essence of person-centred dementia care for nurses in Jersey.

### The Essence of the Phenomenon of Person-Centred Dementia Care

This is care which is:

- Compassionate, showing sympathy and concern for others – but which is restricted by the need to follow specified care plans, is clouded by self-care/preservation agendas, restricted by limited training, held back by nurses not understanding the theory or the philosophy of care and by dualist ideas of self.
- Enthusiastic – but limited to less than it could be by it not being shared by colleagues or prioritized by service directors and their apparent less than enthusiastic support and valuing of the staff.
- Relational – but with relationships often confined to I-It (Buber, 1937/1953) relationships because of the limited expectations of these being mutually therapeutic with a person with dementia, and by nurses' needing to maintain professional boundaries.
- Responsive (to the needs of the other) - but with limited opportunities for openheartedness and judgement-based caring practices (Todres, 2010, 2013) leading to the delivery of care which may not be aligned with nurses' own beliefs and values.
- Respectful – but limited because of the difficulty getting to know the Other in their alterity (Lévinas, 1961/1969) or otherness, (Todres, 2010 p. 273) complicated by dementia and time limitations.
- Embodied – but limited by the priority given to caring for the symptoms of dementia and of controlling these, and by a stronger focus on a person's cognitive ability defining a person, with less emphasis on the

person as embodied (Kontos, 2005; Kontos and Martin, 2013) This was restricted further by nurses' limited conception of themselves as an embodied synthesis of mind, heart, and body and by nurses' professional boundaries.

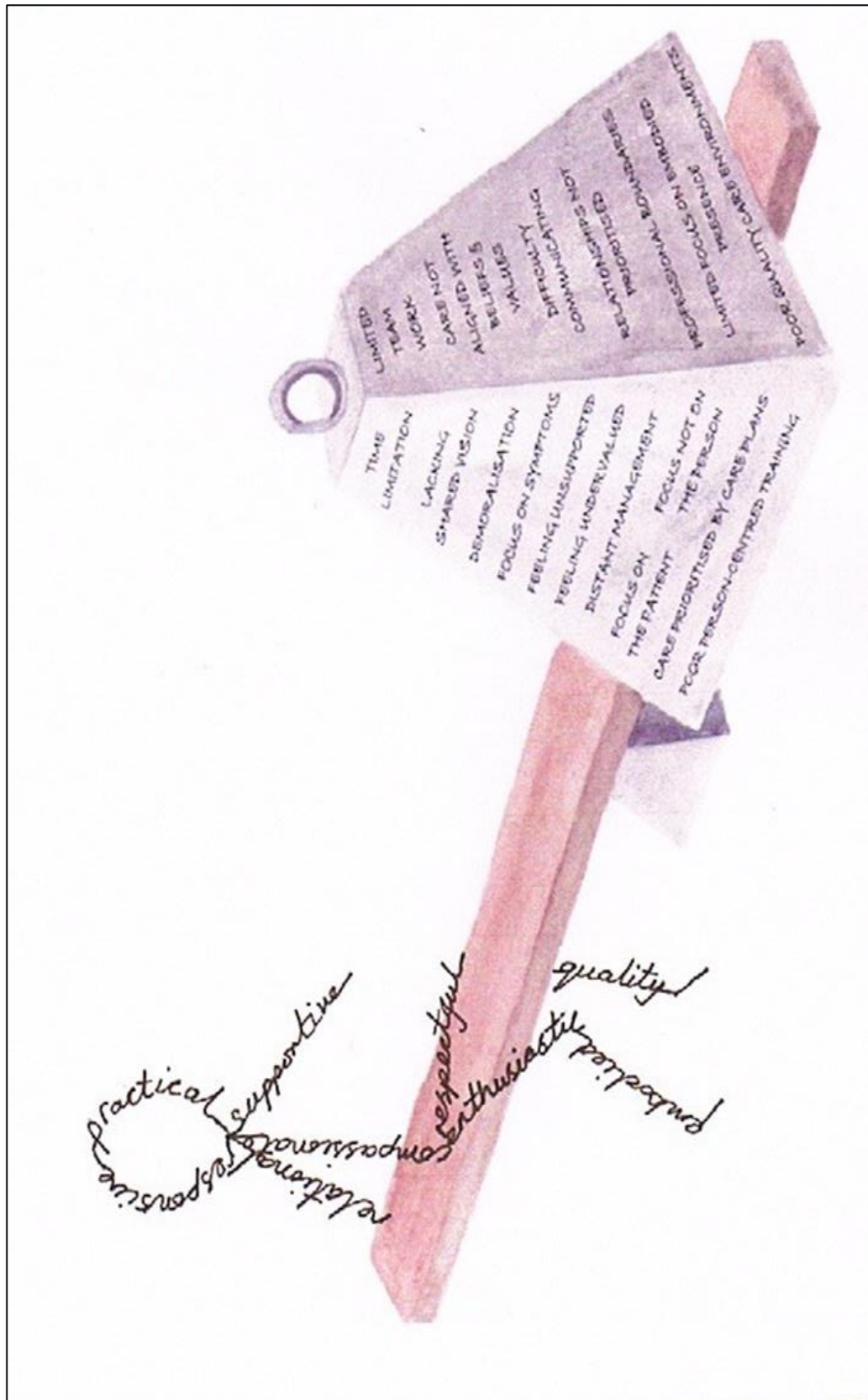
- Quality caring (committed to seeking the best) - but limited by time, insufficient training, encouragement, mentoring, sharing, the care environment and with limited collaborative working or ownership with others (McCormack and McCance, 2010 p. 56).
- Practical (to reduce suffering and increase well-being and mood) - but limited by time and space and personal resources.
- Supportive – but limited by the lack of support the nurses themselves receive, time restraints, resources, the care environments and the system structures.

This research has revealed that these nurses were all compassionate, showing sympathy and concern for others, they were all enthusiastic, they valued relationships and were as responsive to others and their care needs as their situations allowed. They were respectful, supportive and embodied, readily giving themselves in the delivery of the best practical care they could, qualities which Ross et al. (2014) also observed. However, the emergence of these nine essentially positive features was protracted and concealed in part because of negative under-tones that so evidently surrounded them. Therefore while person-centred care for nurses in Jersey is compassionate, enthusiastic, relational, responsive, respectful, embodied, quality, practical and supportive, it is heavily weighed down and therefore limited and restricted by the negative elements nurses encounter in themselves and in the systems in which they work. Diagram 4 illustrates my description of the essence of person-centred care, showing a near useless see-saw, incapacitated by the weight on its right-hand-side. In summary therefore, I propose that the whole see-saw illustration, with both its positive and negative aspects, contributing their 'irreducible making-role', (Barker and

Jago, 2012 p. 136) together constitute the essence of person-centred care in Jersey for these participants.



Diagram 4: The Essence of Person-Centred Dementia Care



## The Summary Meaning

While this whole chapter has been a 'pulling it together' and 'giving birth' of the research, terms that Finlay (2011 p. 247-249) uses to describe this stage in a phenomenological project, this final section of the chapter is the ultimate 'pulling together' to find the meaning beyond the essences (van Manen, 2014 p. 52). Throughout this chapter I have provided descriptions of participants' experiences, then presented the essence of person-centred care, and as a way for you the reader to gain access to the 'meaning-reality' (McCulloch, 2003 p. 105 in Hughes et al., 2006 p. 19) of these, I have offered my interpretative input, often in poetical form.

Again, as before, this final stage of the process retains all of the whispers and song from earlier stages of this research, with the participants' voices joined with mine in the co-creation of summary meanings. I have expressed these as metaphor images (Lakoff, 1987; Romanyshyn, 2013) because of their ability to,

'speak seasonally and in a pivotal way that is neither too dark nor too light', and which,

'approximates those things that could never quite be fully expressed; a writing that intentionally leaves matters in some obscurity', and which,

'is tentative in its response to what asks to be spoken in the work' (Romanyshyn, 2013 p. 317)

but within which there is 'gold' to be found (Romanyshyn, *Ibid.* p. 322).

These metaphor images emerged after re-immersing myself deeply into the participants' experiences yet again, re-visiting my earlier interpretations, re-orientating myself to their 'tone' in a search for new inner meanings (van Manen, 2014 pp. 263-264) that I had not explicitly crafted into my poems, re-focussing and allowing my body to have its say (Gendlin, 1978/2003, 1992) and from some very powerful reflexive attention. From my work with people with dementia, my training as a person-centred counsellor, my observation of

others in their person-centred work, and prompted by a dream I had recently in which I overheard my mum (who died five years ago from cancer) tell a friend that she had dementia, I asked myself a question I have asked many times before. I asked what it would be like losing my ability to recognise places, getting mixed up in time and not understanding people or the things around me. Working reflexively with this and in the light of this research, more so than ever before when I had asked this, I had a sense of desolation and of being quite alone. I then dared to ask myself what I would want more than anything if I had dementia, and what I would be and do for my mum if she were still alive. I knew for certain that constant, dependable, close, embodied meaningful relationships would matter to me more than anything. If I knew people who loved and cared for my mum were there for her, all would be well. I needed to know that there would be someone, if not myself, who would hold my mum's body close to theirs in a comforting embrace, just as Jane, my first participant, had done. This I believe was an exceptional example of person-centred care, but not representative of most care, most days for these participants, but yet I believe it pointed towards the something more, a move from 'I-It' to 'I-Thou' relating (Buber, 1937/1953) and embodied-being-with (Merleau-Ponty, 1945/1962) that they knew, either explicitly or implicitly, was limited yet needed. I sensed this perhaps accounted for the participants' mood and seemingly limited pride in their work and was the 'palpable presence' in the room (Galvin and Todres, 2009 p. 313) helping to reveal meaning, add clarity and turn experiences into images (van Manen, 2014 p. 262). From this ground the shoots of meanings emerged, unfolded their leaves, and blossomed to give their fruit.

As with the earlier parts of this chapter, these summary meanings will also be 'strongly embedded' (van Manen, 2014 p. 45) with further meaning, offering you the opportunity of adding new layers of interpretation to go beyond those offered here. So, finally, encouraged by Finlay to be 'selective' and not aim to report everything, but rather to give 'a sense of what the experience is like – what the lived world feels like', (Finlay, 2011 p. 249) I have arrived at these summary meanings.

Through this process I have intuited that person-centred dementia care seemed something of an unattainable ideal, which had a demoralising, dampening, greying, almost saddening and sometimes disabling affect on these participants. While they all wanted to work more person-centredly and knowing that, or having some implicit awareness, that this could be achieved by a more embodied, relational, being-with people with dementia, these were perhaps in shortest supply, limited by all the elements I have added to the right of the dashes in the summary essences above and depicted in Diagram 4. These included the professional boundaries they believed they had to maintain, the restraints of their limited training, limited investment in services, the lack of clear leadership, the limited time available for caring in the way they wanted, and of feeling alone and unsupported in the task. From this the metaphor images that emerged from the data were of:

- multiple, frail-bodied, almost ghost-like lone rangers on lame horses
- lighthouses, in need of renovation and not linked to the national grid nor featured on any navigation maps
- an orchestra missing some of its manuscripts and without a conductor
- an army with out-of-date weapons and missing a General and other ranks of leadership.

### Lone Rangers

While in this image there are multiple lone rangers, passionate for their cause, they are indeed alone and not riding out together to fight for their cause. Neither do they have faithful companions by their sides for encouragement as The Lone Ranger had in Tonto his American Indian companion. These lone rangers have their own projects in their own lands. While they are recognisably human bodied, their bodies do not have meaty, muscular substance and therefore seem ghostly and frail. Further to all this their means of, and systems for transport to accomplish their missions are nothing like The Lone Ranger's faithful horse Silver. These horses are lame.

## Lighthouses

Lighthouses have been essential buildings to protect, direct and guide shipping for hundreds of years and are obvious features on coastlines the world over. They are robust, built of the strongest materials for their essential tasks. Every part of them from their foundations to their topping lights are seen as integral for the whole and they are finely and constantly maintained from top to bottom to ensure they never fail. While the participants seemed to be bright lights in their work places, these images are of poorly maintained structures with limited effectiveness because of their restricted power source and stand-alone status. They might not even be robust enough in their present conditions to withstand strong winds and rough seas, let alone a storm and ships may get lost because their lights do not reach out to cover the whole coastline. In the UK lighthouses are linked to a national energy supply and cover the whole of the British Isles. They are features on navigation charts and recognisable by their function the world over. The metaphor image lighthouses do not appear on any navigation maps.

## An Orchestra

I love music. It inspires, motivates and usually engages me fully. I cannot escape it, so much so I can never write or study with music playing. It takes me away from my intended task to other places. It therefore has the potential to be transformative. Orchestras are the wonderfully intricate, dynamic, organic, sentient means for the creation of some of the most beautiful music. But their product is not coincidental, accidental, arbitrary or formed by the chance meeting of individuals with similar aspirations to make pleasant sounds. They are instead, a selected group of highly trained, dedicated individuals bringing with them an array of varied instruments in which they have invested years of dedicated practice. Together they then work at coherence, integration, co-ordination and become a 'band of brothers', members of this or that orchestra with a distinct, identifying name. They then 'sing from the same hymn sheet' they play from the same manuscripts, with each section having its own version appropriate for those instruments. They are responsive to the skill and passion of their conductor who is much more

than a figurehead with a baton, but is a leader who embodies the music and is as equally integral to the team as is the third violin player on the back desk. Such orchestras are fuelled by a shared passion for the music. Although each player in the metaphor image orchestra has some musical ability and passion, this orchestra makes a terrible din to anyone's ears. It has no clear direction, no-one holding it together and keeping it in time or sharing his or her inspiration and passion for the music. Some players are improvising as they go along while others look like they have put down their instruments because they have no music.

### [An Army](#)

An army marching to war is a powerful sight. It communicates a sense of triumphant victory even before the first bullet is fired. It is co-ordinated and uniformed with each soldier having the same sense of purpose and hopeful of the same outcome, though each has his or her distinct part to contribute. It is constituted of well-trained and disciplined men and women within stable and well-defined structures of management. Its existence represents a government's commitment to the welfare and protection of its people. Investment in up-to-date weaponry, equipment and training is an unquestioned part of the government's budget. Effective management runs throughout the whole organisation and its General and other ranks of the leadership team are selected because of their experiences of once being on the battle lines themselves and their ability to identify with and communicate with every soldier from the newest recruited private to the Chief of Staff. The metaphor image army has no General and no other evident ranks of management. It therefore relies on its own ideas, skills and abilities, acquired without any significant or structured training. As a consequence of this, confidence is lacking which, in its turn limits its vision and effectiveness. It has no investors because of its detached, leaderless status and therefore has had no investment in its weaponry, other equipment or in its infrastructure, which are out-dated and outmoded.

## Summary of the Metaphor Images

These, like the summary essences all include some strong and positive imagery. The Lone Ranger for example was strong, determined and full of good intentions; lighthouses ensure safe passage through difficult waters and are resilient and bright; orchestras are an eclectic mix of multi-skilled players who together can produce beautiful music; and armies protect and fight for good causes. However, as Barker and Jago (2012 p. 134) suggest, 'qualitative character often encompasses the absence of qualities' quite evident with these summary meanings as metaphor images. These have a negative side to them and are similarly marred, and while I have offered some of my own elucidation of these, I have intentionally limited this to describing the images themselves, so that they retain some further creative space and opportunity for you the reader to engage the third hermeneutic turn and consider your own further interpretations (Romanyshyn, 2013 p. 319; van Manen, 2014 pp. 359-360) and see other meanings. These metaphor images can speak for themselves to you, to bring you even closer to the phenomenon of person-centred dementia care and thereby discover further insights. Such is the amazing creative and re-creative potential of existential hermeneutic phenomenology as a research methodology.

## Summary of Chapter 7

'When you listen to a presentation of a phenomenological nature, you will listen in vain for the punch-line, the latest information, or the big news. As in poetry, it is inappropriate to ask for a conclusion or a summary of a phenomenological study. To summarize a poem in order to present the result would destroy the result because the poem itself is the result. The poem is the thing. So phenomenology, not unlike poetry, is a poetizing project; it tries an incantative, evocative speaking, a primal telling, wherein we aim to involve the voice in an original singing of the world.  
(Merleau-Ponty, 1973 in van Manen, 1990 p. 13).

From the planning stages of this research, to the interviews, through long days in the deep, demanding process of analysing the data and crafting the eight portraits, to the summary existentials and final essences and meaning, I

have almost arrived at the last full-stop of this chapter. This has been a truly 'dynamic, lived process' (Mandic, 2014 p. 164) for me which, as I have drawn nearer to the phenomenon, has been characterised by times of disorientation, familiarity and illumination. Through this it is my hope therefore that while you were 'listening' to my chosen, co-scripted words, you will have felt drawn into the lived experiences of Jane, Sally, Monica, Katie, Sam, Julie, Linda and Katherine and will, in your reading have heard and felt and experienced the 'more' in, and around-about the words, and know that you have already come closer to your 'punchline', your new understanding, and have been changed by whispers and song.

### Waiting For The Song

My worderly, writerly task  
Has been to tune my heart,  
My ears, my eyes and mind  
With such embodied willing,  
For a song  
In the gentlest whisper -  
For a whisper  
In the most touching of songs  
To take its form in print.  
And at times I have thought  
I caught on the breeze  
A sound so faint,  
So distant, unformed,  
A womb-world word  
No more than a syllable  
Awaiting its birth -  
With pregnant waiting time  
For wandering,  
For re-wonder-ing  
What song  
It would become.

'as if the emptiness is full, as if the silence is murmuring, as if one hears the silent whispering of the Real.' (van Manen, 2006 p. 719)

In my next chapter, Chapter 8, I intentionally move away from the participants direct experiences to occupy a different space and a perspective that will enable me to consider the findings from my research on a broader



canvas. Here I will be using the new knowledge from this research, alongside outcomes from similar research, to offer an expanded appreciation of the essence and meaning of the phenomenon of person-centred dementia care and highlight the implications of this for person centred care in Jersey and beyond. However, I will still carry with me and re-turn to the participants' voices to ensure the discussion is grounded in the findings. In Chapter 8 I also return to the philosophical ideas of Martin Buber and Maurice Merleau-Ponty to situate my findings in these, I review the methodology and methods, make some suggestions for further research.

## Chapter 8

Re-membering the Seed and Looking  
Towards the Harvest: A Discussion of the  
Research Outcomes



## Chapter Eight: A Review and Discussion of the Research Outcomes

### Re-turn, Re-view, Re-member

In Chapter 1 of this thesis I presented my research questions and my aims and objectives for this research and then in Chapter 2 I clarified the beliefs and values that accompanied me throughout this work, to the extent to which I was aware of them. The philosophical tenets that provided some important structure were then explored in Chapter 4 and from this I proceeded to describe the methodology in Chapter 5 and then described the methods I developed for it in Chapter 6. Chapter 7 is dedicated to the presentation of the participants' lived experiences of person-centred dementia care and the emergent summary essences and meanings of person-centred care that I interpreted from this data.

Before developing a broader discussion of these findings, my first task in this chapter, like Romanyshyn's as he approached the penultimate chapter of his book (Romanyshyn, 2013 p. 309) is to return to my beginning. This is for the purpose of re-membering what led me into this (Ibid. p. 348) and to attempt to 'return to what the work wants', to re-member those 'moments when the work took hold of one'. In doing this, I intend to 'give(s) up for a moment being the author in charge of the work to become again the one who is in service to it' (Ibid. p. 311) to acknowledge 'the tension between the ego's intentions for the work and the soul of the work' (Ibid. p. 323). This will ensure, as far as possible, I continue to give voice to the experiences and meanings of those who have provided the raw material for my research. So, with Romanyshyn's encouragement, I took time out since completing the last chapter to re-turn, to re-view and re-member the words that first drew me into this research, that then became an 'image' (Ibid.) and through the process of this project, merged with the data, to become a metaphor image for the real, embodied, relational people cared for by my research participants. Directly influenced by the voice of Jane, Sally, Monica, Katie, Sam, Julie, Linda and

Katherine, I allowed the words, the image and metaphor image to work in me anew, the outcome of this creative, hermeneutic re-turn being *Wheelchair Man*, a poem which holds together these combined whispering, singing voices within it.

### Wheelchair Man

Wheelchair Man  
Sits patient-ly,  
Anonymously  
Waiting,  
Fixed,  
It seems  
By the superglue  
Of what, or who  
Has put him there.

Wheelchair Man  
Tell me – please,  
Why are you so  
Silent?  
Tell me your story.  
Talk to me of  
Other days.  
Tell me why  
You do not sing?  
Why you dance  
No more?  
Wheelchair Man  
Please,  
Tell me your name  
Tell me –  
Is there a supersolvent  
Not yet patent,  
Or evident,  
Maybe,  
Conceivably,  
For all one knows,  
To free you?  
Wheelchair Man...

Throughout this research and particularly in this discussion chapter, I am pleased to have had Finlay (2009a, 2009b, 2011; Finlay and Evans 2009) as one of the ‘ancestors’ noted by Romanyshyn (2013 p. 313) alongside me for her encouragement and wisdom. She describes human experience as ‘complex, opaque, ambivalent and ambiguous’ and it is with such qualities that the bedrock of this discussion chapter is formed! Fortunately however she follows this by reassuring researchers and readers alike, that the purpose of phenomenological research is not to present ‘answers’ from such data, which she describes as ‘mess’, but rather that its purpose is to capture something of the complexity of human nature. Thus with radical reflection, focussed discussion and skilful presentation the researcher can ‘bring the phenomenon to life’ (Finlay, 2011 p. 244) through its messiness and come to new insightful knowledge from it. She adds more reassurance saying ‘the best phenomenological accounts’ capture all these aspects (Ibid. p. 232). Merleau-Ponty prioritizes this too by drawing our attention to philosophy as ‘radical reflection’, ‘infinite meditation’ and ‘attentiveness and wonder’ as a means to reveal the ‘mystery of the world’ (Merleau-Ponty, 1945/1962 p. xxi).

So, while the content of Chapter 7 may have seemed rather ambiguous, mysterious or even messy, and lacking in neatly packaged answers, it did ‘answer’ the first two research questions by giving life to the phenomenon in the midst of ambiguity, ambivalences and paradoxes of the nursing experiences I encountered (Finlay, 2011 p. 232). This chapter’s focus goes beyond this and develops more detailed discussions from my enhanced appreciation of these experiences with the expectation of this then impacting upon readers’ specific interests in person-centred care or research, for it to help refine practice, direct services or help theorists clarify issues from this ‘complexity’ and ‘mystery’. In doing this I have looked back to ensure I have continued to represent the participants’ phenomenological experiences, while also developing my own interpretation of the findings as an hermeneutic researcher, visible in the frame as an interested and subjective participant myself, rather than as a detached, impartial observer. In taking this research

into this new space, its potential can be extended to a wider audience in gerontological nursing.

### Introduction To The Discussion

In the light of the metaphor image of *Wheelchair Man* this chapter continues with a discussion of the possible limitations of this research, which is followed by a discussion of the value I have derived from grounding this research in some of the philosophical ideas of Martin Buber and Maurice Merleau-Ponty with some additional insights from Emmanuel Lévinas and Eugene Gendlin. My focus is then directed to the contribution of the methodology and methods I have crafted, followed by a discussion of the findings with which I ended the previous chapter which situates my research within the field of other person-centred nursing research and other phenomenological research, highlighting areas of new knowledge and in some cases confirming other research outcomes. This includes a discussion of the implications of this for nursing and counselling practice in Jersey and beyond. After this I focus on the possibilities for further research inspired by new questions that have emerged as a result of these research findings.

These discussions will be, as existential hermeneutic phenomenology requires, 'tentative, partial and emergent' (Finlay, 2011 p. 244) but pertinent for those currently charged with delivering, leading and redesigning services for people with dementia in Jersey and beyond.

### Possible Limitations of this Research

Because my experience of this process had been mostly positive, which has no doubt fuelled my motivation for it, I was able to remain open to the idea that any obstacles I encountered on the way were part of the meaningful pathway for the research (Collins and Cooper, 2014 p. 92). Therefore, although these certainly needed attention, I believe they did not seem too critical or limit the research too significantly.

## Distance

Before I began to develop this discussion, I felt it appropriate to first give further attention to this idea of 'mystery' and 'mess' to ensure these would have their place alongside the 'infinite' (Merleau-Ponty, 1945/1962 pp. xxi) voices in the data with the possible implications of these. So, again, as at other times throughout the research, I allowed the data to take hold of me, while at the same time incorporating the words 'mystery' and 'mess' along with it, and to focus on the felt sense (Gendlin, 1978/2003) derived from this. Through this I began to feel that this sense of messiness was not only in the data, but was also an embodied felt sense for me too, with the word 'alien' seeming to fit the sense quite well. I allowed this alien presence to find further expressions in my body and from this began to understand that, as a counsellor researching nurses, I was in fact the alien and outsider. Although my work often takes me into care homes and hospitals, and although this research has been supervised by a Registered nurse who is now a Professor and researcher in this field, and although I am a member of a PhD research forum almost exclusively membered by nurses, I was aware that I was looking with a different kind of eyes, feeling with a different kind of heart and sometimes speaking a different language to the participants. This will of course have had its effect on the data, my interpretation of it, the way I have worked creatively with it and how I have chosen to construct this discussion and my priorities for it. In this there has been the paradox of both closeness and distance. While I believe my distance has prevented me being distracted by the whispers and songs of my own lived experience of person-centred dementia care, other researchers researching in their own field of practice, could to some extent be deafened by this and find it difficult to phase this out of their analysis. This meant that although I was clearly an outsider, my position was congruent with the methodology requiring naïve wonder and openness to listen to unique lived experiences. Even with such distance though, I was able to feel some closeness through the relationships that grew as I lingered with the participants for many months through the transcripts and my re-membered encounters with them and into this final discussion. I

sensed this residual closeness most significantly perhaps with Sally and Linda, maybe because of their almost immediate acceptance of me, with no obvious questioning of my outsider status.

It has been interesting to note that it appears I am alone in this 'outsider' status amongst researchers in the field of nursing and person-centred dementia care, as all other such research I located through multiple electronic database searches (including; EThOS; UK PubMed/MEDLINE; Google; CINAHL; ProQuest; and university library catalogues to access on-line journals directly) has been undertaken by nurses practicing within this field or by academics in universities including; McCormack, 2004; Nolan, 2004; Ashburner, 2005; Byers and France, 2006; Dewing, 2007; Nolan, 2007; Edvardsson et al., 2010; McCormack et al., 2010a, 2010b, 2011; Moyle et al., 2010; Clissett et al., 2013; and Colomer and de Vries, 2014.

Because I was aware my rather unique position might limit the appeal of my research for some, I asked an international expert in gerontological nursing, specialising in the theory, models and frameworks for person-centred dementia care to review my research findings. I am confident this will have validated its trustworthiness and the credibility of the conclusions I have come to from the research. So therefore, while appreciating my outsider status, I remain confident in my position and know that I and other researchers, could use EHP as a research methodology in other fields of interest other than our own.

### Interpretative Stance

A further potentially limiting aspect of this research for some readers is its hermeneutic stance. While I believe that interpretation is essentially part of all experience and has the potential to lead to enlightening new insights and knowledge to translate into practice, I am aware that others will not agree with this, including those with a more positivist stance requiring a greater emphasis on quantitative methods and statistical analysis to generate



knowledge (Crotty, 1998 pp. 1-17). They may not be as ready to appreciate the rigour in this research, giving less credit to careful descriptions of individual experience and the richness to be found in participants' interpretations of their experiences of the phenomenon. Furthermore, they may not accept the researcher's interpretations, and be unable to accept that 'subjectivity, when properly handled, actually strengthens the validity of the findings' (Collins and Cooper, 2014 p. 90) or the place of the third hermeneutic element as a reader interprets the data. The researcher's immersion and in-depth analysis for the purpose of establishing new insight and knowledge will be meaningless for some.

Even amongst phenomenologists there is disagreement about this. It is clearly the case that this research, on a 'continuum with pure rigorous, scientific description' and 'fluidly poetic interpretation', (Finlay, 2011 p. 19) is positioned much closer to the latter and will not offer those requiring the 'science-like approach', offering 'fine-grained, normative descriptions' (Ibid.) what they may need. Given this I had to find the confidence, the time and space necessary for the deep engagement with the data that this methodology requires to provide its rigour, which because it is always subjective and infinite, and can never be considered complete and definitive. Another approaching the same topic, with the same questions and participants, may have heard and interpreted this differently and most certainly the outcome would have another style (Todres, 2007 p. 56). This meant there was the tension between knowing, and not knowing fully if the work was truly hermeneutic phenomenology with the potential to lead to new understanding. The realisation for this will of course be individual for each reader and the quality and style of my writing will be limited in its fruitfulness for some readers, while for others it will hopefully feel like an easy read, and be accessible and enlightening, achieving all its initial aims. The burden for this is not all mine however as the readers must, in their turn, within this methodology, remain open to the hermeneutic potential in themselves, to re-

interpret and re-imagine so they are able to hear the more distant whispers and songs that have eluded my ears.

### Existential Nature

The existential nature of this research embraces unique, individual experiences that are coloured through with the participants' own inflections, tones and accents. This research does not therefore seek generalisations or even intentionally to organise the data into themes for further analysis,

‘but rather indicates possible themes that help our understanding move together in that vital space between commonality and diversity’ (Todres, 2007 p. 57).

While, like Galvin and Todres, I believe that,

‘the evidence of real experiences provides a kind of credibility that only human stories can give’ (Galvin and Todres, 2013 p. 35)

there are those for whom ‘statistical truth’ rather than ‘narrative truth’ (Spence, 1982 in Galvin and Todres, 2013 p. 35) with large sample sizes or participant numbers, offers the authenticity and rigour they require. This research does not provide a ‘numerical snapshot of averages’ (Galvin and Todres, 2013 p. 35) and the relatively small number of ‘humanly textured scenes’ with ‘aesthetic qualities of living’ (Ibid) may seem meaningless for some.

### Time

Time had its part to play, mostly in reflection’s, reflexivity’s, creativity’s and writing’s ability to eat up time with their ferocious appetites. There was never enough of it and always a reason to spend more of it. Van Manen warns of this writing,

‘The eloquence of the texts may contrast sharply with the toil, messiness, and difficulties involved in the research/writing process. “And this took that long to write, you say?” “After seven drafts!?” (van Manen, 1990 p. 8 – van Manen’s punctuation).

He obviously understood, and along with Romanyshyn (2013) provided the encouragement I needed to put my pen down and consider the project both completed and yet also incomplete, with more words 'still growing in the silence' (Romanyshyn, 2013 p. 345).

This research is therefore limited because, unlike some other methodologies, it can never be considered as the final word on its subject, there will always be more that could have been said, or written in a different way, or said with a changed emphasis or even different punctuation to provide an alternative perspective. Romanyshyn uses the terms 'wounded' and 'mourning' and writes of the need to 'let go of the work' (Ibid.). While the researcher must experience these real, limiting burdens, it is this stepping back and letting go, of time being up, that enables the reader to then take up the 'pen' to begin their re-creative development of the text. The theoretical base of this research encourages such 'dialogue', so the limitation of 'time being up' for this work can be balanced with the possibility of such re-creation after dissemination with newer voices joining in the singing.

### Poetry and Style

Following on from this, I must also accept that poetry, although now more common in hermeneutic phenomenological research (Prendergast et al., 2009; Galvin and Prendergast, 2012) may have limited its appeal for those who do not appreciate poetry, or find it inaccessible and therefore a barrier rather than a gateway to further interpretation. Its style is important too. With some poetry I tend to find myself becoming deaf, so expect that there may be readers who might suffer in the same way, also limiting its potential to speak and offer new insights into the lived experience of person-centred care. However, because I was aware of this potential limiting factor and because I did not consider myself a master-of-the-art of poetry, I did seek guidance from an established, published poet who read many of the poems I have included in this thesis, who commented upon their style and accessibility.

Inevitably though, what may be light-rays of illumination for the landscape of my research for some, others may experience as heavy, dark clouds.

### Participant Numbers and the Research Context of Jersey

Although Jersey follows many of the trends in health care seen in the UK (Alzheimer's Europe, 2013 p. 95; States of Jersey, 2012b, 2014) and although 50% of its population are immigrants, mostly from the UK, (States of Jersey, 2015) this research was carried out exclusively in Jersey. Therefore while the outcomes may reflect something of the experience of person-centred dementia care in the UK, this cannot be presumed. Furthermore, while I believe that the range of participants' backgrounds and employment contexts brought a colourful array of lived experiences to the research, others would have had different stories to share, their songs remaining implicit whispers in this research. So, while the outcomes of this research are location and participant specific, I am confident that the new knowledge and insight from this is significant, that it offers inspiration for new questions to emerge and indicates the need for further research. In this way, what may be a limitation is also a positive place for growth. This has been my experience. From the three initial research questions, I am now nurturing many new research interests, some of which I have outlined later in this chapter, and the necessarily specific subject matter of this thesis, can be extended by readers' further research.

### Openness and The Need To Answer The Research Questions

Finally, there has been some tension between the need to adopt an attitude of open wonder and creative expression required by the methodology, and the need to retain the focus of the research on answering the research questions in a certain style and format. This has probably limited the chances of serendipitous discoveries and insights, though may also have prevented me from travelling too far down dead-ends and catching too many red herrings. The research questions and the methodology have therefore mostly worked together to provide both structure and restraint but may also have

been responsible for the loss of some potentially interesting new insights or knowledge.

### [Incorporating Tenets from the Philosophy of Martin Buber and Maurice Merleau-Ponty, Emmanuel Lévinas and Eugene Gendlin](#)

Fundamental to this research have been the philosophical tenets of Martin Buber and Maurice Merleau-Ponty that I first outlined in Chapter 4. Martin Buber's focus on the primacy of relationships for being in the world and of understanding being gained from real and observable experiences in relationships with others in the world, have been part of the backbone to this thesis (Buber, 1937/1953, 1947/2002, 1957/1974, 1966). Equally important have been Merleau-Ponty's ideas of embodiment, the non-dualist, pure synthesis of a person, a 'self' as 'body' (Merleau-Ponty, 1945/1962). Throughout the fieldwork I was aware of myself as an embodied presence very much with the participants, and not in some abstract, academic, conceptual or detached sense, but rather as my 'vehicle for being' (Merleau-Ponty, 1945/1962 p. 82) in the research. Further to this the idea of 'chiasm' (Merleau-Ponty, 1964/1968 pp. 130-155) of being intertwined as flesh of the same world, together with Jane, Sally, Monica, Katie, Sam, Julie, Linda and Katherine and the people for whom they cared, was important. This helped me appreciate the inseparability of all our life contexts, which helped to extend and maintain my interest and engaged me more deeply.

### [Embodied Epistemology](#)

An embodied epistemology that unified my 'thinking and feeling, knowing and being' (Galvin and Todres, 2013 p. 183) was essential for this research where sometimes I hardly knew if I was thinking something or just 'knew it' in my flesh, and where communication was not only verbal but also embraced the semaphore language of our bodies and the 'felt sense' of an idea or thought (Gendlin, 1978/2003). However, while I was very aware of myself as embodied, this research indicated that the participants, particularly perhaps Katie, Sam and Julie, did not share this understanding for themselves or

people with dementia, probably because it was a concept with which they were unfamiliar rather one they had rejected. Similarly the research indicates that the participants, apart from perhaps Katherine, had little opportunity to discuss the concept of personhood and relate this to their person-centred care. Instead of understanding people as embodied, most participants' relating seemed to be more 'I-It' (Buber, 1937/1953) with the 'It' being symptoms, declining cognition and disability and of managing these, rather than relationships being with embodied others. I believe this might be part of the reason for the heaviness I sensed in the participants. A focus instead on personhood as embodied as proposed by Merleau-Ponty (1945/1962) and on disentangling the 'self from the cognitive categories upon which it is presumed' (Kontos and Martin, 2013 p. 3) could offer lightness and a 'hopeful construction of the body' (McCormack and McCance, 2010 p. 13) to challenge these views. Related to this, Cayton's belief that 'people with dementia are not going backwards' or 'round in circles' but 'are going forwards, on a journey' (Cayton, 2006 p. 285) and Dewing's research offering an example of embodied personhood in people with dementia who 'wander-walk', showed a sense of purpose as they made choices and expressed feelings (Dewing, 2007). These also offer the opportunity to move away from the ideas of loss, negativity, decline and despondency associated with declining cognitive ability that seemed so evident, particularly for Monica, Katie, Sam and Julie.

### **Intertwined Flesh of the World**

The idea of being flesh of the world anchored me in, and helped me to see myself as intertwined and inseparable from the worlds of the participants and those for whom they cared, having been created from the same 'earth'. This principle of embodied connectedness meant that I myself, others in the world, and the world itself, could be transformed by each other (Heß, 2012 p. 26). Although Lévinas' idea of the alterity and asymmetry of the 'Other' (Lévinas, 1961/1969) kept some sense of the mystery of the unknown, I nevertheless could approach this research more easily with a sense of

equality with the participants, while still maintaining the researcher-participant relationship that set us apart as different. However, the data indicated that some participants, particularly Katie, Sam, Julie and Linda, had little sense of a shared identity with the people for whom they cared, but instead communicated the dualisms of, them and us, carer and cared for, staff and patients. Furthermore, the participants appeared not to have considered the idea of alterity, that another person could not be fully known to them. This was evident in the data with most of them seeming to believe that person-centred care stipulated that they should 'know' the person for whom they cared. They acknowledged that they often did not 'know' a person as they believed they should, reasoning that this was attributable to time limitations and other restrictions preventing this. Further to this, there seemed to be some naïve sense that this could be achieved through 'life story work' alone as a feature in a care plan, undertaken by activity co-ordinators. The data therefore suggests that attention to such philosophical discussions should form part of any new training programs or practice development in person-centred care in Jersey.

### Non-Dualist Ideas

It was also helpful to consider Merleau-Ponty's non-dualist ideas of the body, as 'I am it' (Merleau-Ponty, 1945/1962 p. 150). Although he did not specifically describe this as the inseparable intertwining of body mind and spirit, I found this helpful to remind me that I would come to understand more about the phenomenon by my subjective experience of it through my body as my means of being in the world. I was therefore tuned in to the 'mutual partaking' by my 'various sensibilities' to see with my ears, hear with my heart, feel with my eyes and be touched by words (van Manen, in Madjar and Walton, 1999 p. vi). This philosophical ground cautioned me to remember the futility of attempting to think with my mind only, and of attempting to disengage my heart while listening to the participants, but equally not to attempt to listen with my heart only, or without reference to my body and the language with which it could speak. I was however interested to note the

extent to which some participants, particularly Katie, Sam and Julie, engaged in Cartesian dualisms as they approached their work, with much of what they described of their experience reminding me of the first rounds of the Hokey-Cokey action dance when only a part of the self is 'put in' to care. However, I did sense that some participants, in particular Jane, Sally, Monica, Linda and Katherine seemed to want to engage more fully, and I wonder if Merleau-Ponty's idea of embodied presence was implicitly known to them though was missing theoretically and in practice, with some seeming to indicate that they took their bodies to work with them, rather than being embodied beings with presence at work.

### Relationality

Every aspect of this project was relational, from the seed of *Wheelchair Man*, first planted in me by someone else that initiated its growth, to every part of it since. Buber's focus on this helped me to appreciate that relationships underpin all life and care, and has helped me to consider the different types of relating and movement towards others in which I engaged throughout this project, and for the participants and the people for whom they care. It helped me focus on the wealth of new understanding that I could access through being in relationship with others. My world, and others' worlds could be expanded and become more colourful by accessing each others' experiences through such relationships.

In the light of the data from this research, I found Buber's emphatic belief in the potential of the relational to be particularly interesting. He said that, by living being a 'continually renewed relational event' it would be possible to,

'build a special conception of space, dwellings for God, and dwellings for men, and fill swaying time with new hymns and songs, and shape the very community of men.' (Buber, 1937/1954 p. 54)

I was struck by this beautiful language and the metaphors because what so many of the participants seemed to be experiencing were certainly not 'song-



filled' work places 'swaying' in the gentle rhythm of life and these were never described as 'communities' in any positive sense as Buber had done. This spoke very eloquently of the disconnection between work place cultures and the expectation that nurses deliver person-centred care and therefore of the need to firstly understand the primacy of the relational in being, and to bring such concepts into value based work and to find ways to develop 'continually renewed relations' between staff, managers and people with dementia.

In summary, this research indicates that participants' experiences of relationships were more typically 'I-It' between themselves and other members of staff and management and frequently so between themselves and the people for whom they cared. This seemed to be because the focus of interactions was on the accomplishment of tasks that needed to be done to bodies, with the resultant objectification of those bodies, rather than for promoting personhood. While Buber did not consider all 'I-It' relationships to be inferior to 'I-Thou' relationships, he made it quite clear that if a man lived with 'I-It' relationships alone he would not 'be a man' (Buber, 1937/1953 p. 34). Rather than this being concerned with gender, I think Buber here was referring to the type of relationships necessary for personhood to flourish, meaning that 'I-Thou' relating was essential for this. Similar ideas have been proposed by Stoddart (1998) who said that, people become the people they are by entering into relationships, which lead to personal growth that is not dependant on reflective or cognitive attributes. From the process of this research and from the data, I could not agree with Buber and Stoddart more, and believe significant attention needs to be made to foster such relating, but also with consideration for the possible effect of the lack of reciprocity with some relationships that Gove et al. (2016) have drawn attention to in their study.

### Meeting the 'I' in the 'I-Thou'

Further to this, through the process of this research requiring me to ask myself the question 'Who am I?' I have come to believe 'I-Thou' relating

requires, not only a movement towards and meeting with the 'Thou', but also a meeting with, and understanding of 'I', that is oneself. This deepening of understanding, together with the data from the research, indicate that by incorporating values based reflection and encouraging reflexivity in education, I-Thou relating could become more of a reality between staff and the people for whom they care.

### Summarising the Philosophical Framework

Focussing on the philosophical ideas of Buber and Merleau-Ponty, and also of Heidegger, Lévinas, Gadamer, Gendlin and Vanier has been eye-opening and pivotal in this research. This has also confirmed beliefs I have held for a long time but perhaps only implicitly, and has re-shaped much of my thinking on these subjects. This has provided me with renewed confidence and rich new depths to be mined. Attention to these ideas has also helped to generate some of the deeper analysis from the findings and to confidently suggest possible ways ahead for the future of person-centred care.

In summary, this philosophy has directed this research and helped generate new knowledge, which will be discussed later in the chapter by,

1. Successfully integrating different ideas from Buber, Merleau-Ponty, and also Lévinas and Gendlin.
2. Drawing attention to the lived body and its capacity to speak.
3. Drawing attention to body language as a research tool to assist in the interpretation of meaning.
4. Focussing on research as an embodied process and drawing attention to its notable absences in the lived experience of person-centred care.
5. Focussing on the relational aspects of the research methodology.
6. Drawing attention to notable absences of the relational and the concept of embodiment in person-centred dementia care.

### A Methodology and Methods for Research

## Introduction

This project has confirmed the potential of an EHP methodology and methods to yield incredible findings and to elucidate more in taken-for-granted phenomena. This has not been so much by 'action' but by the riches harvested from a 'listening gaze' (van Manen, in Madjar and Walton, 1999 p. v) with passivity and receptivity, embracing wonder and questioning which together have brought new insights and pointed towards areas for growth, development and change.

In my attempt to look at the phenomenon as if for the first time, before I began the fieldwork, I was required to examine my beliefs and assumptions concerning person-centred care and consider the potential influence of these on this project. Because of my growing belief that such research is better undertaken wholesomely, and that 'subjectivity, when properly handled actually strengthens the validity of the findings' (Collins and Cooper, 2014 p. 90), this was not an arduous task. I took it seriously though, continuing to remain as aware of my emotional responses as possible (Ibid. p. 91) while trying to rid myself of my 'tendency to immediately interpret' (Crotty, 1998 p. 96) being aware that I would have my 'forestructures' (Heidegger, 1953/2010) and 'shadowy pre-understandings' (Crotty, 1998 p. 97).

Because of this welcome of subjectivity and my openness and reflection throughout, this project is distinctive in its style and makes a contribution to phenomenological methodology and methods. While this is not replicable, other researchers in various fields of inquiry, including counselling research, may nevertheless develop it with their own perspectives, incorporating as I have done, an existential approach, the use of six existentials as lenses for rigour in the data analysis and the hermeneutic use of poetry and metaphor images to develop meanings.

From further reflection, I am confident that the methods I used to gather my data were not at all arduous for the participants, even though none had

previously taken part in such research and were unaware of the methodology. I am therefore confident that this approach would be useful for other researchers with participants without research experience. Further to this, many of the participants, including Jane who said she felt 'encouraged and lightened' and Katie who said 'it's things like this which helps to develop our practice', appreciated the opportunity this had given them to share their stories and to be heard, when they had not previously had the opportunity to do so.

### An Existential Approach

An existential approach can contribute to a rich understanding of a phenomenon with individual experiences leading to a fuller and deeper understanding of what applies 'generally and typically' (Todres, 2007 p. 7). Although not new in phenomenological research, such sustained focussing on individual experience, apart from a limited number of research projects (Todres and Galvin, 2005, 2006; Kindell et al., 2014) is not often adopted by researchers who more commonly opt for techniques using grouped data to search for recurring themes (Kvigne and Kirkevold, 2003; Adams, 2006; Day and Higgins, 2015).

I am confident however that this research has shown that by staying close to the individual's rich textured, deeply personal stories, much can be learnt about the phenomenon from a person's unique experience of it. This is not about average, general or typical experiences, but about real, lived experience. Once this has been established the researcher, by staying close and at the same time stepping back and sensing the data more wholly, can discover more, leading to further new knowledge.

### Six Existentials

I achieved this joint aim of both stepping back from, and remaining close to individual's experiences by using the lenses of the six existentials of corporeality, relationality, temporality, mood, spatiality and materiality. This

has been fundamental to the methodology and methods and is, I believe, one of the first research projects to make use of six existentials in this way. From vast literature searches (including EThOS, UK PubMed, MEDLINE, Google, CINAHL, and ProQuest etc.) it is evident that all other research using existentials to date has only employed the four existentials of corporeality, relationality, temporality and spatiality (Hayne and Yonge, 1997; Dewing, 2011; Farcus, 2012; Wilson, 2012; Rich et al., 2013) that van Manen cited in his earlier literature (1990, p. 101). More recently however van Manen (2014 p. 306) suggested a fifth existential, materiality, to help guide existential inquiry. I chose to incorporate this having become aware of his new focus and because the data itself was leading me to believe this would be significant. Further to this my attention was also drawn to Galvin and Todres' additional existential, mood, (Galvin and Todres, 2013 p. 29) largely because the data seemed heavy with mooded tones calling out for attention. In using all six I did feel like a pioneer using a cutting-edge, untested navigational aid, but having now completed the data analysis I am confident each brought their distinct contributions, though at times their over-lapping and intertwining was so intricate they seemed less distinct, sometimes seeming that all six were present in just a few words.

### Poetry and Metaphor Images

While poetry is now beginning to feature more in qualitative research (Prendergast, 2009 p. xxi in Prendergast et al., 2009; MacDonald, 2015) it is still not widely used in health research, many researchers preferring more descriptive methods (Hansebo and Kihlgren, 2001; Koivisto et al., 2002; Stenwall et al., 2007; Gove, 2016) that do not include the hermeneutic development of texts to find meanings to be expressed poetically or with metaphors.

This research therefore goes against the grain of some phenomenological research, offering an alternative perspective in its hermeneutic phenomenological methodology. From all the literature I drew on, it appears

that poetry is rarely used in gerontological research (Miller et al., 2015 p. 410) with even less focussed on the lived experience of dementia or dementia care and using the combined voices of the participants' lived experiences with the researchers interpretation of these as vox participare (Prendergast, 2009 p. xxii). Further to this it is certainly pioneering in its use of metaphor images to develop meanings from the data, while allowing the reader a third hermeneutic turn to add their alternative interpretations to the metaphors presented.

### Summary of the Methodology and Methods

Although I was aware that this methodology and methods were unusual and that I was 'taking risks' (MacDonald, 2015) because of the openness and creativity intrinsic to it, necessitating I relied upon my creativity to flow from the data before the data ever came into being, I was nevertheless excited by the potential in this. Furthermore, even though this methodology and methods are still so rarely used in health research, I did not doubt its ability to meet my research aims and objectives. When I initially researched possible methodologies, this EHP methodology seemed the most natural choice, with its existential focus on lived experience and its hermeneutic quality with the possibility of entering into the creative realms of poetry and metaphor. In summary therefore, this research contributes an innovative methodology and methods with its combined,

1. Existential focus on individual lived experience
2. Use of six existential lenses for rigour in data analysis
3. Use of poetry to describe lived experiences and its hermeneutic, interpretative stance with the further extensive use of poetry, metaphors and metaphor images, to present essences and meanings, as voices through which the data may continue to whisper and sing.

## From Lived Experiences, Essences and Meanings to New Knowledge, Implications for Practice and Suggestions for Change

My intention in Chapter 7 was to present the data in such a way to bring participants' lived experiences close enough for readers to feel 'touched' (van Manen, 2014 p. 373) by the phenomenon and to come to a newer experience of it through the essences and meanings I interpreted from the data. This has therefore 'answered' my first two research questions. The third question remains,

'How can an enhanced appreciation of the 'concrete everyday experiences of people be used more centrally to underpin care' (Galvin and Todres, 2013 p. 30) and thereby make a positive contribution to person-centred care in Jersey?'

In the next five sections I take hold of the essence and meanings of person-centred dementia care derived from the participants' experiences and from these make five specific observations and offer five ways in which person-centred care could lose some of the rhetoric that surrounds it and become a more vibrant, effective reality. These include a focus on; ignorance, naivety and rhetoric; education and practice development; on care as a noun; on the physical care environments; and communication, support and a shared vision.

### Ignorance, Naivety and Rhetoric

While there seemed to be an aspiration to make care more person-centred, which Linda said needed to move out of 'the dark ages', the participants seemed to have only a naïve understanding of its associated theory, evident in Sam's comment 'we do that here', an outcome that was clear in Colomer and de Vries' (2014) study and which Clissett et al. (2013) also reported in their study in an acute hospital context. Further to this, I had no sense of any of the models or frameworks developed by Nolan et al. (2004), Brooker (2007), Ryan et al. (2008) or McCormack and McCance (2010 and 2016 in

print) from Kitwood's initial ideas for change (Kitwood and Bredin, 1991; Kitwood and Benson, 1995; Kitwood, 1997) even being present, let alone embedded in, or used as tools for directing a culture of care. This supports Dewing's concern of more than a decade ago, that models and frameworks may not be translated into practice (Dewing, 2004 p. 42) and that,

'many practitioners can 'talk' person-centred care, yet struggle to illuminate it' (Dewing and Pritchard, 2004 p. 178)

and Sheard's view that such terms are being used far too loosely (Sheard, 2010 p. 3) and there is too much focus on 'doing' person-centred care rather than 'being' person-centred (Sheard, 2016). McCance et al., are in agreement stating that,

'The term 'person-centredness' is used freely within health and social care. Yet some argue that the use of this term is an example of tokenism by those using it, because they use it without any real sense of what the term actually means.'  
(McCance, McCormack and Dewing, 2011)

These views are also confirmed by Edvardsson et al. who stated that,

'current understandings of the concept largely rest on abstractions, conceptual synergies and personal opinions.' (Edvardsson et al., 2010 p. 2612)

Moyle et al. (2010) also found discrepancies between best practice models of care and the care people with dementia received which did not always take account of their individual needs (Ibid. p. 426), which again was implicit in this research and also indicated by Borbasi et al. (2006), Cunningham and Archibald (2006) and Nolan (2006).

The participants in this research certainly seemed to have varying, apparently internalised, self-constructed, simpler 'models' perhaps as Edvardsson et al. suggested, being based on personal experience of what constituted person-centred care. These seemed unique to each participant, and perhaps important to some extent, as each was able and happy to talk about their experiences of 'person-centred care', or as Linda called it



‘personal-centred care’, throughout the interviews. However, it did seem that what most participants were describing were contexts and experiences which resembled a fusion of some components of person-centred care but which were predominated by a more medical model of care than person-centred care, with the participants referring to the people they cared for as patients rather than, for example ‘people with dementia’ or ‘cared for people’ such discrepancies also having been recorded by Colomer and de Vries (2014) in their research.

Also recorded in the descriptions of the care they delivered were clear indications that this was primarily governed and prioritized by the content of care plans, written by medial staff, rather than being initiated or directed by the cared for person themselves, or the HCAs or nursing staff involved in the day-to-day care of people with dementia. Although there is significant evidence that care focussed on the person rather than the plan can be more effective than routine care (Webster, 2011) there seemed little room for people to be involved in creating their own care plans or for these to incorporate intuitive or heart-led actions in response to a person’s situation at a particular time, except on rare occasions when time seemed less constrained or when participants’ own determination to see a project through prevailed, as the book project described by Sam.

There seemed very little sense with any of the participants that the primary aim of their person-centred care was the enabling of personhood. I sensed that while the participants seemed to ‘believe’ in person-centred care as a ‘gold standard’ described as such by Katie, and wanted to deliver quality care for people with dementia, it did seem surface-deep for most and perhaps not related to their own beliefs and value systems. There is evidence that when care is aligned with these it can be delivered more authentically, resulting in a greater sense of personal wholesomeness. I therefore suggest that, to help ‘operationalize person-centred care’ (Venturata et al., 2011 p. 252) any new training, education or practice development should clarify the need to move

away from the long established language and practices associated with the medical model and to introduce more values based, reflective training by including dialogue and study of personal beliefs, values and ethics, as described by McCormack (2016). Furthermore, because this data indicated significant differences in participants' descriptions of their person-centred care, I suggest this should include opportunities for nurses to reflect on their understanding of the words 'personhood', 'care' and 'relationships' and the implications this has for person-centredness and showing how these meanings are located in the models or frameworks to be used.

Baldwin and Capstick (Eds. 2007 pp. xxiii-xxiv) however cautioned against a move away from the medical model to embrace person-centred care without the corresponding shift in practice. Kitwood himself also conceived a possible future in which the positive changes could be 'obliterated' with care being 'varnished by eloquent mission statements' (Kitwood, 1997 p. 133) if there was not a corresponding shift in the culture of care. Likewise, Mearns and Cooper (2005 pp. 160-161) cautioned against models where the person is not kept at the centre, believing such models can also become ways of managing people. They cite the example of an ABC model where the A=the problem, the B=the model designed to meet a need for care or treatment and C=the outcome. In such a model the person is invisible and all there appears to be is a problem, a method of treatment or care and a hopeful outcome. This is not the essence of person-centred care but something of this appears to have emerged from these lived experiences of nurses in Jersey, indicating the need for an enriched understanding of person-centred care to begin to change the culture of care.

This research also indicates that the policy makers' and managers' adoption of the term 'person-centred', evident in all the most recent H&SS documents (SoJ, 2008a, 2008b, 2011a, 2012b, 2015) describing plans for new services, and all hospital wards and care homes caring for people with dementia, points towards a naïve appreciation of what this really means and what it

entails in practice. Interestingly, the King's Fund reports similar findings, stating that 'trainees receive some limited training in this area (patient-centred care) only to find that this is not modelled by senior professionals in daily practice' (Foot et al., 2012 p. 8). Alternatively, it is possible that this could be a function of their poor communication of their understanding of this, or a lack of attention given to promoting this and providing appropriate training for these participants. Whatever the reason, there seemed to be some obvious rhetoric associated with this, outcomes also evidenced in Venturato et al.'s (2011) study in Australia, which must be addressed.

### Education and Practice Development

A tension that seemed clear as I worked with the data was that, while most of the participants seemed to indicate that they considered the care they delivered to be good enough, there was also an impression that they aspired to improve, to express more of what Banner refers to as 'true regard for the Other' (Banner, 2014 p. 98). However the possibility of change seemed illusive, possibly because they believed they did not have the means for change, or they were not prioritizing this perhaps because there was no requirement or encouragement for them to do so. Within student nurse education in Jersey, courses for health care assistants and further professional development in the work place, there are very few courses that are described as offering any person-centred care components and there are no practice development options. Further to this, what courses there are, are short, from only two hours to two days, with much of the content focussed on defining dementia, the symptoms of it, with some reference to life-story work, focussing more on what people 'did', not on 'who' they are, and with minimal reference to 'being' person-centred or the notion of promoting personhood, outcomes also reported by Colomer and de Vries (2014 p. 9). Moyle et al. (2011 p. 189) in their research advocate the need for courses in person-centredness to replace training programs focussing on physical deficits, a concern similarly expressed by The King's Fund who recommend that 'communication skills are incorporated in all curricula' (Foot, 2012 p. 8) and

Deloitte and the Alzheimer's Society in their joint project reviewing dementia care also state their concern that 'education may be restricted to facts of education rather than experience of training' (Deloitte and The Alzheimer's Society, 2015 p. 10). This situation clearly needs addressing for there to be a change in the culture of dementia care, which Featherstone et al. (2004), Galvin et al. (2010), Venturato et al. (2013), van Wyk et al. (2014) and Barbosa et al. (2015) show can be facilitated by differing targeted education. Nolan et al. (2008) say this also needs to include relational centred approaches and Beer et al. (2009) and Dewing and Dijk (2016 p.119) qualify this in their reports, saying that any new courses must be given significant investment and be well taught, and McCance et al. (1999, p. 1393) add that these should have clear, simple messages to ensure a significant move away from the apparent 'quick fix, low level training' (Dewing and Dijk, 2016 p. 119) to a focus on long-term sustainable action and culture change. Drach-Zahavy (2009 p. 1471) is also concerned about the potentially short-lived, limited benefits of training, which her research indicates may result from the over-use of technology, productivity pressures and financial limitations. Hughes et al. (2008) emphasise the importance of training in developing the confidence people need to be able to care well, and Moyle et al. (2011, p. 186) and Moniz-Cook et al. (2000) in their research found that this also increased job satisfaction and staff morale. The limited educational and development opportunities in Jersey may therefore go some way to explaining the tension participants seemed to be expressing when the care given in their work places seemed to fall short of the standards to which they aspired, alongside their perceived lack of resources, as also highlighted by Edberg et al. (2008) in Australia, Sweden and the UK in their research. Furthermore, there is some evidence (Moyle et al., 2010) that to affect a whole work-place culture of care and organisational change, management structures and teams need to embrace a shared vision through joint training, and that such training should not be 'mechanistic' nor 'de-moralise(s)' the 'careworker and the work' (Kitwood, 1998 in Baldwin and Capstick, 2007 p. 330). This idea of the absence of shared visions seemed so clear for Linda summarised well in 'I'm

trying to tell 'em over here what I've seen in UK', by Katie's position as a lonely 'figurehead' and with Sally being called 'unique'. There is also evidence that work must be in partnership with, and collaboratively between, all services (Clarke et al., 2014) and further, that there should be appropriate understanding of the unique culture of each work place before there are any innovations or developments in the learning culture (McCormack et al., 2011). Before any of this however, Balfour and Clarke (2001) say that dissatisfaction with status quo is a prerequisite, and clarity about the nature of the problem with some sense of the direction is needed for change.

Interestingly, my experience of person-centred counselling education in Jersey has been very different. The three courses that formed the basis of most of my initial learning were over five years and included skills practice, role-play, value-based reflection, reflective writing, personal study, discussion and supervised placement work. The emphasis was on developing person-centredness to promote therapeutic relationships, including empathy, unconditional positive regard (a non-judgemental stance) congruence and presence, with learning to be attentive to body language and developing the ability to intuit meaning from focussing on the body. This was not just about concepts and theory, but was also about shared experience and with the 'thoughtful resources of the practitioner' (Todres, 2008 p. 1570) with her 'own authentic voice amid the choir of voices from yesterday' (Hansen, 2010 p. 163) resulting in 'something larger than knowledge and evidence' (Ibid. p. 1573). Because of this striking contrast in education and what I observe in my colleagues' sustained person-centred practice, I suggest that those charged with developing courses for health care professionals should consider integrating some aspects of counselling education, as part of a move away from the focus on physical deficit in the biomedical model.

I would also suggest that research should be undertaken to review all person-centred training and education in Jersey to establish the number of people who have accessed this and to then engage in an evaluation of its

effectiveness. By increasing access to training and education, providing practice development, focusing on the models and frameworks for practice, developing person-centredness and person-centred skills for individuals and teams, I believe that this would go some way to addressing some of the issues outlined above and promoting person-centred care in Jersey, as proposed by Manley et al. (2008) and Harding et al. (2015 p. 11) in their studies.

Although Dementia Care Mapping (University of Bradford, 2005) was used for a while to evaluate the effectiveness of person-centred care in Jersey, it was discontinued because of its complexity, costs and the need for it to be carried out by skilled evaluators. Given this, apart from some feedback forms for attendees at the training sessions mentioned above, there is now no evaluation of person-centred care undertaken in Jersey, making it hard to establish the effectiveness of the present training options and of any changes. This absence also means that Jersey may be missing the opportunity such measures can provide to 'drive up the performance of the system' (Collins, 2014 p. 16). Therefore, as suggested by Beer et al. (2009) Harding et al. (2015) and Wilson and McCance (2015) there needs to be some new means of evaluating this, with new evaluation methods, perhaps linked to the person-centred outcomes from McCormack and McCance's Person-Centred Framework (2010 and 2016 in press) or Nolan et al.'s Senses Framework (Nolan et al., 2004) or perhaps more simply by asking and observing if care is embodied and relational in healthful cultures.

### Care as a Noun

This research has indicated that the last 'C' in PCDC is experienced more as a noun, a thing, and not primarily as embodied, relational being-with people with dementia as on-going interaction to express 'kindness' (Mast, 2014 p. 169) or as embodied communication (Kontos and Naglie, 2007). Care was more like a 'job' (care work or nursing work), with, for example, Katie describing herself as a nurse, 'set apart' as 'the person in blue' with a uniform

for 'impact', and Sam often listing things she 'had to do' when describing her experiences of care, and the poem *A Day's Meaning* describing Julie's action plan's for her day. These findings are similar to those of Norman (2006) who found care to be something people 'did' mostly with their hands, perhaps experiencing a dualistic role by becoming nurses at work, and leaving themselves, or something of themselves at home, cut off to some extent by their professional boundaries.

'Caring' is the present participle of the verb, meaning something quite different to the noun 'care'. 'Caring' can be used as an adjective too, which, like the present participle, I believe better represents the intended essence of PCDC, inferring active, embodied and 'attentive being with' (Post, 2000 p. 3) empathy and presence, or sympathetic presence, (McCormack and McCance, 2010 pp. 100-103) and not a tick box agenda of things that must be done to meet the criteria of a certain type of care, something of which seemed to be described by some participants. Brenner and Wrubel discuss this idea of caring being more than a theoretical standard to be reached, saying that it is a 'profound act of hope' to make things better (Brenner and Wrubel, 1989 p. 404) a standpoint also held by McCormack, stating 'caring benevolence' cannot ever be 'forced or be ticked as done' (McCormack, 2003 p. 204) but its 'mood' should be obvious, even though unquantifiable (McCormack, 2016). 'Care' as a noun does not call out in the same way for the body and for relationships as 'caring' does, either as a present participle or an adjective. Thus, by changing the emphasis from person-centred care to person-centred caring, that is, from noun to adjective or present participle, I wonder if there would be a subtle shift, helping nurses to embrace this concept as a way of enabling personhood through empathic, relational, embodied, presence with people. Further, with such a shift to 'caring', away from tasks needing to be done to, or for 'patients' (a plural noun which may risk people becoming objects in receipt of care, thus ignoring their subjectivity and their thoughts and feelings) I wonder too if this may then be embraced more as 'caring about' 'people'. Like McCormack and McCance, I

believe this has the potential to foster a sense of caring as an affect, which 'relates to the idea of caring as emotional attachment', instead of 'caring for' which is more about 'providing some sort of service' (McCormack and McCance, 2010 p. 25). In our technologically driven and target focussed health care systems both in Jersey and the UK, I believe care in which the person remains the focus is even more critical and needs to be addressed. Any means that limit the possibility of people becoming objects of care (Cowdell, 2010) which Buber (1937/1953) describes as 'I-It' relationships, and which Baron-Cohen states as being 'the worst thing you can do to another human being' (Baron-Cohen, 2012 p. 5) has to be considered in contexts in which people with dementia are being cared. Buber qualified this notion though, and in conversation with Carl Rogers said that 'There is something objectively real that confronts you' (Buber, 1965 p. 173) both 'in the person' and 'the situation'. This statement I believe points towards some the tension evident in the nature of relationships for the participants. Person-centred care promotes the idea of sharing in care and of equality (Nolan, et al. 2004; Brooker, 2007; and McCormack and McCance, 2010 and 2016 in press) yet the participants seemed aware of an inequality in the power they had and in the systems of care that decide upon and directed the care given, and also in their experiences of the subtle differences between the person in need of care being objectively real and being objectified.

These are significant issues that came to light by working interpretively with the data. Because of the apparent tensions in the participants' experiences of person-centred care, and of these being only 'person-centred moments' (McCormack and McCance, 2010 p. 137) I propose these should be pursued in value-based reflection with a focus on the qualities of being and caring. This more reflective approach could facilitate caring with fewer tensions, with more attention upon emotional connections and the 'traditions of care and compassion' (McCormack, 2016).



## Physical Care Environments

All the participants commented upon the care environments in which they worked. For example, Jane quite forcefully suggested that the building was only 'just about fit for purpose', Sally talked of the tensions she experienced between herself and other staff who did not value the care environment as the residents' home, Monica stated that 'there should be more changes' and seemed to yearn for these, and Linda struggled to make the care environment 'homely' because of its lack of personal space and opportunities for privacy. All participants said that the care environments affected their relationships, with the buildings, the arrangement of spaces, the equipment and facilities located within these and the organisational systems in which they worked, not being conducive to the delivery of the sort of care to which they aspired and were un-'healthful' environments (McCormack and McCance, in press 2016). For some time now it has been well documented that care environments will impact upon staff and people with dementia, affecting the nature of care that is possible, and having the potential to limit or enhance such care (McCormack and McCance, 2010 p. 29-30; Moyle et al., 2011 p. 189). The aim should be for places of work and care to be 'therapeutic environment(s)' (McCormack et al., 2015 p. 3) but it seems that most participants did not believe these to be therapeutic or healthful, with some even suggesting them to be detrimental to the physical and mental health of both themselves and the people for whom they cared.

Although there have been some recent improvements to some States' care environments, with some participants acknowledging these as positive, there was still considered to be more room for improvement. At present (2016) the States of Jersey are considering massive investments in new health services including building a new hospital at the cost of over £400m. While there are some proposed improvements to mental health services, in which services for people with dementia are located, most of these are for developing care in the community and make only minimal reference to services for people with dementia. In these emergent plans it is proposed that H&SS in-patient

care for people with dementia will continue to be located in these much older buildings and not within the proposed new hospital, apart from when acute medical or surgical treatment cannot be provided there. Although it is suggested that more research is needed to explore the affects working environments may have on staff and their ability to deliver quality care (Moyle et al., 2011 p. 189) I suggest that care for people with dementia will continue to be affected while retained in buildings not designed for the purpose of excellent person-centred care and quite literally situated 'in the shadow of the asylum'. This location perhaps points towards some of the residual stigma to which Brooker (BACP, 2011 p. 51) referred and may be perpetuated if not located within new, purpose-built buildings and alongside other care. While a well-designed building is not the only part of the care context necessary for the delivery of person-centred care (McCormack and McCance, 2010 and 2016 in press) I suggest that those involved in the hospital's design, reconsider the location and quality of the care environments for people with dementia, before such plans are quite literally set in stone.

### Communication, Support and a Shared Vision

From listening to the participants and reflecting on the data, I became aware of a clear sense of detachment between those charged with directing the services, the managers and the care staff, findings similar to those reported by the Care Quality Commission (2013) and by Colomer and de Vries (2014). Communication between these seemed limited and there certainly was no sense of there being a shared vision and nothing resembling 'constellations' or 'communities' of practice that Rycroft-Malone et al. (2015 p. 14-15) suggest to be necessary for the implementation of ideas, or of working to the same agenda with the same ultimate aim of promoting the well-being of people with dementia, and certainly not for the well-being of staff. There seemed to be no obvious relationship, or communication pathways between service designers, senior managers, managers and other staff, and certainly no sense of embodied presence or even virtual presence together. Each seemed remote from the other, displaying little of the structure Røsvik et al.

(2011) have shown to be most conducive to person-centred care and which Clissett et al. (2013) say needs to be embraced by individuals, teams and organisations. I reflected on this separation for Jane in my poems *She Finds It Better* and *Unthinkable Comforts*, and the lack of a shared vision for Sally was clear as she feared that inspectors, who did not have the same vision for care, would 'close down' her care environment, and Katherine spoke of 'management' who only saw people as 'jobs to be done'. Further to this, some of the participants seemed to rely on their own determination, self-encouragement and seemed to be patting themselves on their own backs rather than being supported through the strength of team-working, mutual encouragement, and by practical indicators like comfortable facilities for staff, promotion or pay incentives.

Kitwood, as far back as 1997, dedicated a large section of his book *Dementia Reconsidered* to such issues throughout care organisations. He wrote,

'Caring at its best, springs from the spontaneous actions of people who are resourceful and aware, able to trust each other and work easily as a team.' (Kitwood, 1997 p. 103)

He continued,

'If employees are abandoned and abused, probably the clients will be too. If employees are supported and encouraged they will take their own sense of well-being into their day-to-day work. Thus, if an organization is committed to providing excellent care for its clients – if it is committed to their personhood – it must necessarily be committed to the personhood of all staff at all levels.' (Ibid. p. 104)

Following this Kitwood dedicated whole sections to 'stress, strain and burn-out', the experience of which he said results in 'low-level functioning' 'psychological disengagement', situations where there is 'no longer an attempt to do all the job really requires' and where there is 'criticism of anyone who does more than the accepted basic minimum.' (Ibid. p. 108)

I believe that much of what Kitwood, and also Brodaty et al., (2003), Ashburner (2005) and Byers and France (2008) highlighted is evident in the

data from this research, which could be, in part, directly attributable to staff feeling, unsupported in their work both practically and emotionally, under-resourced, missing out on training, demoralised, working in poor environments both for themselves and the people for whom they care, not part of a team and often stretched to their limits.

Kitwood suggested that, to facilitate a change in the culture of care focussed on personhood, staff needed to be taken care of including, appropriate 'pay and conditions of service', being 'properly rewarded for their work', have an 'appropriate induction process' including 'supervision' and 'guidance and support' (Ibid. p. 109). Deloitte and The Alzheimer's Society in their joint project also drew attention to this as a possible inhibitor of change stating that so often 'care homes employ predominantly low-skilled and low-paid social care staff' (Deloitte and The Alzheimer's Society, 2015 p. 13) with poor pay and conditions leading to high turnover rates (Ibid. p. 11) twice that of any other industry (Myska, BBC Radio 4, 24.11.2015).

Kitwood also spoke of the relational aspect of caring within the workforce saying that 'care is much more than a matter of individuals attending to individuals' but that the team 'should ideally be aligned in their values' with 'shared objectives', views also expressed by Røsvik et al. (2011) and Webster (2011). Kitwood (1997) cautioned that this would not happen spontaneously and that if it was absent, cliques would form and some aspects of care would be avoided. He also wrote of the 'vital' need for supervision, and the opportunity to discuss difficult situations, 'in-service training' (Ibid. p. 110) 'individual staff development' 'accreditation and promotion' and 'effective quality assurance' (Ibid. p. 111), views that Ashburner (2005, pp. 295-296) and Brooker (2007 p. 20) also forcefully champion. Interestingly, some of these issues were aired on BBC Radio Jersey (15.09.2015) by the Chairman of the State's Health Scrutiny Panel, who was attempting to explain the poor levels of recruitment and retention of nurses in Jersey (Renouf, 2015). The levels of stress and the lack of support

to which Kitwood referred, and which the participants in this research experienced, were not mentioned as contributing factors in this interview, but were found to be very clearly related in research by Moyle et al. (2011 p. 189). Part of Kitwood's solution, not mentioned by Renouf, but was by Mesney on the same program last year (Mesney, 2014), was the vital need to employ 'the right people' (Kitwood, p. 112) in roles that are compatible with their beliefs and values (Ibid. p. 113) with 'that *prise de conscience* that is of the essence of all highly skilled practice' (Kitwood, 1998 in Baldwin and Capstick, 2007 p. 330). While training, education and practice development may help to promote aspects of person-centred care, having beliefs, values and attitudes congruent with such care is an essential prerequisite, which Nilsson et al. (2012) also support, which can then be nurtured by 'personal confidence and courage' and a 'reflexive concern for others' (Kitwood, 1998, in Baldwin and Capstick, 2007 pp. 322-331). Kitwood has been supported in this more recently by Nolan et al. (2004) and Ryan et al. (2008) with similar ideas, in their Senses Framework, which focuses on the need for staff (and people with dementia) to have a 'sense of; security, continuity, belonging, purpose, achievement, and significance'. Kitwood however went further by stating that,

'Any organisation which claims to be providing person-centred care, but which is neglecting these, (care for the staff) is certainly making fraudulent claims.' (Kitwood, 1997 p. 142)

Kitwood did not leave his readers without pointing towards a means for achieving such vast ideals, even though he appreciated that 'person-centred care is out of step with many trends of the time' including 'standardisation and cost-cutting', (Ibid. p. 115) a situation also addressed by Dewing (2004 p. 39) and Clissett et al. (2013) and 'industrialised' a term used to describe care in a recent BBC Radio 4 (24.11.15; 1.12.15) documentary. Kitwood's belief that person-centred care 'now has a moral force that should not be underestimated' seems the key to change even with the real,

'challenge (being) to get organisations actually to do it, rather than

simply maintain a façade'. (Kitwood, 1997, p. 115)

The removal of the façade, evident in the data, and to begin the process of re-embodying the frail-bodied, of healing lame horses, of illuminating and restoring lighthouses, of printing new music and finding a conductor, and of equipping a leaderless army, is the first task and must be alongside the second, an appeal to that 'moral force' to show its strength.

I have quoted Kitwood at length here because I believe he almost perfectly described many of the situations experienced by the research participants and the rhetoric clothed façade that has become evident. Lindseth and Norberg (2004 p. 148) say that reflection on lived experience, to name and to understand meaning before any policy changes can be implemented, is essential. This research data indicates a need for change and I propose an appropriate starting place for this might be the formal appointment of a Clinical Lead in Dementia, a position which does not exist, even in the more recent plans for improvements (SoJ, 2012a, 2012b, 2012c). Managers coming to an agreed definition of person-centred care, as Drach-Zahavy (2009 p. 1471) suggested necessary for improvements in patient-centred care, could also facilitate improvements in person-centred care and with the formation of an Island Dementia Strategy much like the National Dementia Strategy (DoH, 2009) and the Glasgow Declaration (Alzheimer's Europe, 2014) change could be embraced more effectively. Although some uncertainty remains concerning the efficacy of the National Dementia Strategy, largely because of underinvestment and it being non-mandatory (Hilton, 2010) if a Jersey strategy became mandatory, received adequate investment and was signed by Jersey's Chief Minister and Health Minister, all H&SS Service Directors and ward and care home Managers, I believe this could be a first step to uniting in a shared vision for person-centred dementia care in Jersey and a means for the 'moral voice' to show its combined, public voice and strength.

### A Summary Reflection of this Section

As a means of summarising this section, I want to return to the essence of person-centred dementia care I proposed in Chapter 7 and link this to rainforests. I will explain. About a year ago I watched a documentary series called *I Bought A Rainforest* (BBC 2, 2014). Wildlife photographer Charlie Hamilton bought a large area of the Peruvian rainforest hoping that he could stop loggers illegally cutting down trees. The series followed his attempts to protect the land, the trees and the wildlife living in them that he had grown to love. He immersed himself not only into the forest but also into the lives of those who were engaged in the illegal logging business, listening to them describe their lived experiences of life in the forest. The beautiful camerawork left the viewer in no doubt that Hamilton became an embodied, flesh-of-the-same-world-presence together with the loggers in that world. Before the process of listening and immersion, Hamilton had previously described the loggers as “bastards, bloody bastards” because of their destructive acts, tearing apart the forest and the wildlife he loved. By the end of his immersion into the loggers’ experienced world, he ended the series with these words, “The bastards aren’t bastards, they’re actually really nice people”. He had come to understand that what they were doing was what they could, with what they had around them, and were kind, family-focussed people like himself. He surmised that if he had generations of forest life in his blood, he would be one of them. His new vision was gained by means of his embodied presence alongside them and through the relationships that developed because of this.

I have a passion, not so much for rainforests, but for people with dementia. From my perspective, as an ‘outsider’ looking in on person-centred dementia care, from HCP’s conversations to me (as the one quoted in Chapter 2, which painted the first brush strokes of the metaphor image of Wheelchair Man), and from my multi-coloured background of beliefs and values (also described in Chapter 2), I had some opinions about person-centred dementia care in Jersey. Through the process of this research and through immersion

into others' lived experiences and having heard their quiet whispers and songs, my song now has a newer melody and some new lyrics. There is need for significant change in Jersey, but these participants are 'nice people' and are mostly doing, like the loggers, their best in their circumstances.

So, in conclusion, this research has shown that person-centred care in Jersey is far removed from the glossy mission statements of the private and public sectors, with many of the components of the person-centred models and frameworks referred to in this thesis clearly missing, from the macro context to person-centred outcomes, with only some little evidence of the theory attempting to be put into practice by some participants who aspire to be more person-centred but whose person-centred care is restrained. Their whispers and song are lost amidst the powerful mechanical sounds of out-dated systems, poor communication, lost visions, inappropriate training and education and missing support systems.

This research indicates that to develop a 'dance' of some 'beauty' with a 'beat and mood' (McCormack, 2016) that is Jersey specific, but also with possible implications for person-centred care in the UK, there is,

1. A need to embrace a new understanding of person-centred care from the macro context to individual practitioners to enable a change in the culture of care.
2. A need for effective training, education and practice development.
3. A need to embrace a new vision, perhaps focussed more on 'caring' than 'care' and a commitment for this from all parts of the service, which I propose to be in the form of a Jersey Dementia Strategy.
4. A need to support nurses, including improved working environments, emotional support, mentoring and improved communication with managers.



## Implications for Counselling Practice and Research

When I considered the aims and objectives of this research, a fourth objective beyond my initial three assumed some importance. This was to remain alert to my lived experience of this whole process and to consider how this might inform my practice as a counsellor and as a research methodology for counsellors and other therapists. The following is the outcome of this consideration.

### Introduction

Phenomenology is still only 'emergent' and described as 'baffling' and 'strange' (Finlay, 2011 p. ix) amongst counsellors as a research methodology. While I was initially baffled by its language and the various interpretations there are of what constitutes phenomenological research, I have found it more baffling that so few counsellors take up research using this methodology when it seems to fit so well into, and encompass so much of both counselling theory and what is natural in counselling practice. From the perspective of having now nearly completed this thesis I can wholeheartedly endorse this methodology for my colleagues.

### Lived Experience in Counselling

Although some psychotherapy may seek to find reasons for peoples' distress or the problems they face and solution-focussed therapy might look for solutions for the problems people bring into counselling, much of counselling aims quite simply to accompany people through their lived experiences of life and to help them find richer or newer understandings by exploring and coming closer to these through reflection over time and in the company of a journeying 'friend' (Rogers, 1980; Merry, 2002; Feltham and Horton, 2006; Sanders, 2006). Counsellors do not usually ask questions beginning with 'why', but like existential hermeneutic phenomenology, they more usually help people explore the lived experiences of life they bring to counselling with 'how...' or 'what...' questions. These questions are exploratory, helping point towards newer understanding rather than pointing out, or providing

explanations or statistical summaries of life. From having witnessed such questions providing new insights and becoming the means for significant change in counselling, I could trust that my research questions could do the same and as an outcome of this research I will now endeavour to give such questions a clearer focus in counselling. I also now feel more firmly anchored into my work with philosophy and practice in much nearer proximity to each other, where previously this relationship had been only implicit and not as developed as it is now.

### Embodied Presence

Essential to this research, has been the embodied presence of one person with another. This is the starting place for most counselling where empathy, unconditional positive regard and congruence are the core conditions of this meeting, leading to the development of a therapeutic relationship. In such relationships the counsellor listens attentively to others who tell their 'stories' of pain, hurt, anger, sadness, loss, lostness or suffering. Together, the counsellor and the person they are counselling, then reflect on what is being said, with the possibility of further understanding being intuited from their body language and the felt sense of the body (Gendlin, 1973, 1978/2003, 1992). While both body language and focussing on the felt sense, to make more explicit that which may have been hidden in the depths of a person's being, have been important in my practice for some time, this project has helped me appreciate that I have perhaps paid more lip-service to these than I was aware. By making space and time for, my 'speaking body' as a welcome presence in this research, I appreciate now that in my practice I have not travelled to this wealthy landscape as much as I could have done, where insight and direction can be found in more than spoken words.

### Empathy or Sympathetic Presence

Empathy is a healing balm which has the potential to 'solve problems' (Howe, 2013 p. 18) and 'resolve conflict, increase community cohesion, and dissolve another's pain', and interestingly, in the light of the ideas I expressed in

*Wheelchair Man*, is described by Baron-Cohen as ‘a universal solvent’ (Baron-Cohen, 2011 p. 132). In person-centred counselling theory, the method is said to be ‘completely dependent on understanding the world of the client’, (Sanders, 2006 p. 45) accessible in part through the empathic being with others. This meeting with others and immersion into the others’ worlds was as equally part of the methodology and methods for this research as it is in my practice, so it was familiar to me and therefore will be as accessible through this familiarity to other counsellors. I will therefore certainly be promoting it as a methodology with methods likely to be accessible and congruent with other counsellors’ ontological and epistemological preferences. However, this project has also helped me to appreciate that while all life is essentially relational, (Buber, 1937/1953) embodied, (Merleau-Ponty, 1945/1962; 1948/2008) never existing in isolation from others, and that immersion into others’ lived experiences can bring insight and understanding, I have also become more aware that there will always be asymmetry in such relationships (Lévinas, 1961/1969; 1998/2006) and that some mystery will remain. The alterity of the ‘Other’ means that he or she can never be fully knowable to me. I will always be the ‘I’ in I-Thou relationships (Buber, 1937/1953) seeing the world from the perspective of my own embodied self, with the ‘Other’ seeing me from his. Therefore, as an outcome of this project, I will be ‘Listening with simple ethical openness – without pre-supposed totalizing knowledge of the client’ (Krycka et al., 2015 p. 9) as my focus for being therapeutic, sustained by ‘a philosophy of responsibility’ (Ibid. p. 8) for the ‘Other’.

### Bracketing and Researcher Subjectivity

In person-centred counselling,

‘empathic understanding involves a process of ‘being with’ another person, that is, attempting to ‘step into the other person’s shoes’ and ‘see the world through the other person’s eyes’, laying aside one’s own perceptions, values, meanings and perspectives as far as possible.’ (Merry, 2002 p. 79)

Before beginning this research, I had wrestled with this idea of 'laying aside' in my practice and found that while it was theoretically pleasing, I believed it was practically impossible and ultimately, if relationships were to be empathic, congruent, I-Thou meetings, I believed the 'real' me needed to be face-to-face with the Other. However, before beginning this research I did not have the language to express what had to remain only as an embodied sense, or the philosophical ground on which to construct my practice to encompass this belief. Since being required to examine my beliefs and values for this research and anchor then philosophically to find a congruent methodology and methods, I have certainly felt more confident and affirmed in my practice. I therefore found the debate concerning the reductions, to bracket or not in research, (van Manen, 1990 p. 175, 185) to be enlightening and extremely interesting and one with which I willingly engaged and in which other counsellors will equally well engage.

### Interpretation

Tentative interpretation (Merry, 2002 p. 78) is another commonality between EHP research and counselling, where after immersion into the client's life, a counsellor might offer a possible, though always tentative, interpretation of the client's situation. Together this is then reflected upon and either accepted to bring further enlightenment or is rejected. Like EHP research this is never analytical or definitive, and while a counsellor does not intend to be a healer hoping to solve problems, this is often what the person coming to counselling might hope for. Because of the need to engage so acutely as a listener for discovering meanings for my research participants, as for Morrow (2009 p. 237) I believe this has helped me learn to listen to my clients in a different way. In my practice, particularly early on in a counselling relationship, I am now more focussed on listening for the meanings people make of their lives rather than the 'facts' of them or helping them look for solutions in the first instance.

## Listening

My listening now incorporates more attention to my embodied being in relation with my clients and to the qualities of this being, and is less dependent upon my head-knowledge and counselling skills. A further outcome is that I am finding I now spend more time in reflection and working reflexively following counselling sessions, as though this is a continuing listening. This feels as though I have the transcripts of these in my hands, as I did with the transcripts of the research interviews, which I read over and over again. This is something I had not done to the same extent before, preferring to experience the moment of each session, but am now encouraged to do so because of the wealth of new insights that came from such reflection. This is a further positive outcome from this research for practice.

Furthermore, because I regularly listen to people describing experiences and situations that I have never experienced myself, I could relate this to my 'outsider' status of not being a nurse working with people with dementia using person-centred care. My counselling experience imparted some confidence that I would still be able to immerse myself into the worlds of the participants that were quite different to my own, and from this I can also confidently promote this methodology amongst other counsellors and in fields of research outside their own immediate practice.

## Focussing on the Relational

Research indicates that there is no model of counselling more effective than another (Jackson, 2016 p. 8) but that it is the depth of the relationship that is established between the client and counsellor that holds the key for change (Cape et al., 2010; Glove et al., 2010) and offers the client the opportunity to share at depth. These relationships are deepened over time but practiced counsellors are usually well resourced to develop these quickly. I am convinced that part of the reason the research participants seemed happy to engage with me at such depth, and so seemingly easily, was due to my

confidence and experience in meeting new people as they share their life experiences in such contexts. However, I had perhaps become accustomed to this in the counselling context so was initially surprised that the participants, from another profession to my own, willingly shared with me. This caused me to reflect upon the enormity of this privilege and the trust people placed in me, which I feel I now never want to take for granted. Because this is essential in counselling practice, counsellor researchers should be encouraged to embrace this methodology and methods.

Because of these commonalities between counselling practice and this methodology, and because I love its honesty, and the fact that my beliefs and values are comfortably at home in both, one of my first tasks once this research is completed, will be to actively promote it amongst my colleagues. In undertaking this research I have not had to pretend to be who I am not, or to be 'neutral' and I have not had to use the language of academics that would not fit with my 'mother tongue'. My professional practice has certainly benefitted by this project.

## Indications for Further Research and Planned Publications

### Introduction

During the process of this research and from its outcomes, it has become evident that, while there has been considerable research focussed on family members' experiences of caring for a person with dementia, (Todres and Galvin, 2006; Mei-Chun et al., 2012; Wareing-Jones, 2012; Kindell, et al., 2014; Cabote et al., 2015) there is a need for much more qualitative research focussed on nurses and other HCPs and their dementia care work, a position supported by other researchers from around the world including; McCormack, 2004; Ashburner, 2005; Innes et al., 2006; McCormack and McCance, 2006; Byers and France, 2008; Edvardsson et al., 2010; Pol-Grevelink, et al., 2012; Sellevold et al., 2013; Carmody et al., 2015; Harding et al., 2015; McCormack, in Harding et al., 2015 p. 94; and Dewing and Dijk, 2016.

Certainly for me, there are now more questions I feel inspired to ask, beyond the initial three with which I began this project, all of which are now fighting for my attention to be actualised into new research. This forms part of my discussion chapter because, although at this stage they are not formalised into distinct projects, remaining for now chrysalis-wrapped or seed-like, they are part of the harvest of this research directing my gaze towards regions where new meaning may originate and percolate through the 'porous membranes of past sedimentations' (van Manen, 2007 p. 12). The five following ideas are now infusing me with their possibilities so much so that I am beginning to hear faint new whisperings.

### 1. Word Meanings

Through the process of this research I have become increasingly more interested in words and the potential they have to limit, extend and colour meaning. This has encouraged me to consider concept analysis (Walker and Avant, 2011) as a methodology to reflect more on the words directly attached to my field of study and to consider how people may understand their meaning differently. This I consider may be partly related to people's differing cultural backgrounds or training and education, but may be subtler than this. I am particularly interested in the meanings attached to the words 'care' and 'caring' which to me are quite different as I have described above, but within which there may also be multiple individual variations for each. It would then be interesting to discover if either one may enable person-centredness to be more easily understood and practiced.

In the light of this research and a recent study by Wiechula et al. (2015) I suggest this idea should be developed further to explore the possible link between nurses' understanding of the caring relationship and the meaning they attach to the terms 'care' and 'caring' and 'person' and 'personhood' and 'dementia', which may be related to and influenced by the contexts in which people work. Wiechula et al. suggest the possibility of this being linked in

both positive and negative ways, and which I believe may be influenced by nurses not understanding the philosophical framework of personhood on which person-centredness is built and the practical application of this in person-centred care.

## 2. Lived Experiences Beyond The Jersey Context and Beyond Person-Centred Dementia Care

This research has shone a bright light on the lived experience of person-centred care in Jersey. Although Jersey prides itself on its differences with the UK, I believe that, given the negatively weighted revealed essences and similarly tarnished metaphor images for meanings that this research has revealed, similar research is imperative in the UK.

Furthermore, by extending such research to include a study of the lived experiences of other types of care, helpful new insights may emerge to form a clearer picture of person-centred care. With this interest in mind I have already spoken with researchers at the Fuller Graduate School in the US concerning their on-going research focussed on experiences of carers of people with disabilities in 147 L'Arche communities in 46 countries worldwide and await their outcomes (L'Arche, 2016).

Developing this idea and based on my experience of person-centred counselling and the apparent ease with which I perceive this being translated into practice, I consider it may be helpful to consider person-centred counselling theory, training and its application to inform person-centred dementia care. The importance of developing skills for being person-centred is central in this, together with personal reflection, skills practice and close attention to understanding the philosophy on which it is built. McCance et al., (1999) see this as necessary, as does Nouwen, returning to the word's origin 'kara', meaning 'to share in the pain' and then considers the question 'What is care?' (Nouwen, 2011 p. 16). This is the starting point for most person-



centred counselling practice, which may have important implications for dementia care.

### 3. Adapting Existing Models

Although 'person-centred' is a widely used term in nursing and health care (McCormack, 2006 p. 472; Brooker, 2007 p. 11; McCance et al., 2011 p. 1) this research has shown that participants were often unclear about its meaning and none made any mention of the models and frameworks for this, indicating perhaps that these were either unknown or misunderstood. Because other studies support this (Stewart, 2001 p. 1; McCance et al., 2011 p. 3) I suggest it may be necessary to research the accessibility of these models and frameworks and if it appears that it is their complexity that is contributing to their disregard, to then consider creating simplified versions of these, or perhaps giving renewed attention to them alongside the more theoretical aspects of person-centred care in training and education.

In the light of my experience noted in 2 above and from this research, role-specific models designed separately for HCAs, nurses, nurse practitioners, managers and service designers, might lead to a clearer understanding of person-centred care for people in their specific roles. For example a model for HCAs might focus on the qualities for being person-centred, and a ward manager's might include this detail but also incorporate the social and physical environment, skill mix, developing relationships with all staff, power sharing and so on, with the Person-centred Practice Framework (McCormack and McCance, 2010; 2016) being appropriate for policy makers and service designers.

I anticipate that most would have a narrower focus and might also include facets from other care philosophies shown to lead to good outcomes for cared for people. For example, this might include facets from the Picker Institute's Principles of Patient-Centred Care, and I would consider drawing upon my own experience of having spent time in 3 L'Arche communities in

France and England (L'Arche, 2015a, 2015b) where people with disabilities including dementia live. In these the focus of living is on relationships, acceptance, compassion, belonging, sharing, interdependence, community (with an obvious sense of embodied being together), transformation and growth, occupation, equality, and mutual giving and receiving of care between people with and without disabilities. All 3 communities were peaceful places of welcome, which may help inform our person-centred care of people with dementia.

#### 4. Differences In Role Identities

I am interested to discover if changes in practice are influencing nurses' identities as nursing seems now to be more of a profession and perhaps less of a vocation for some, particularly as more nurses are now trained to degree level, are managing other care staff and more are becoming nurse practitioners and prescribers, roles which may reduce the time actually spent with people with dementia. From my time spent with these research participants, observations during the course of my work and the experience of being a patient, I am concerned that any possible tension with multiple expectations to be carers, managers and highly skilled clinicians, may be restricting or complicating the delivery of person-centred care.

#### 5. Person-Centred Care, Personal Philosophy and 'Nature'

Some participants seemed to understand, and perhaps were able to be, more person-centred than others and in their own words, to 'get it', even if they experienced some resistance in its actual practice. This caused me to consider if this was a reflection of 'who' they were, their nature, their beliefs and values, their life philosophies or ethic of care, perhaps having more of the attributes listed by Manley et al. (2011), the ability to form relationships (Innes, 2006) or having a positive attitude to people with dementia which Norbergh et al. (2006) suggest promotes better person-centred care. I believe this could be significant if person-centredness is more dependent on the intrinsic presence of such attributes in the person to facilitate such care,

rather than on other aspects of the macro context, some aspects of the care environment or training and education.

For this reason I believe further research is important, the outcome of which could have significant implications, not only for training and education, but also for recruitment criteria. This might also then relate to the concerns expressed by McCormack (2004, pp. 36-37) and Polkinghorne (2004) that there may be little distinction between person-centred care and good, quality, intuitive heart-led care.

### Future Publications

Because I am confident this project has born its fruit in meeting its aims and objectives through the data and its analysis in Chapter 7 and with this discussion, I consider it is important to disseminate its findings. This will be to share its methodology, data and outcomes, and also to stimulate further discussion and potentially inspire other researchers to take hold of and develop the ideas I have outlined above. My initial five-point plan for sharing this knowledge is outlined below.

1. To present an overview of the study including its methodology and findings to readers of *Dementia. The International Journal of Social Research and Practice* and the *Journal of Clinical Nursing*.
2. To report the findings of this research and its implications for person-centred practice to readers of *The International Journal of Older People Nursing*.
3. To write an article focussed on the methodology and its suitability for counsellors to use in research. This would be appropriate for readers of the BACP research journal *Counselling and Psychotherapy Research, Linking Research With Practice* and for the National Counselling Society's *NCS News*.
4. To write three summaries of this research, one for the research participants, another for practitioners in Jersey and a third for managers and policy makers in Jersey.

5. To write an article promoting the use of poetry in phenomenological research, incorporating some of my poems and those of other researchers of comparison and diversity.

### Summarising This Section

A central feature of EHP research is its unknown destination at its beginning and its dependence on openness throughout the process for wondering and re-wondering, wandering and re-wandering ('erring' a little perhaps, Heidegger, 1971/1975 p. 186) and for the inspirational flames from this to spark off other fires along the way to help direct and guide what the project will become. Part of this process should lead to newer flames and newer paths to walk, as I believe this research has done, as outlined above.

### Chapter Summary and Summary Contributions to Knowledge

I have undertaken this research with the aim of helping you the reader, and indeed myself, 'make contact with' and so to be 'touched by' (van Manen, 2014 p. 373) the phenomenon of person-centred dementia care and thereby come nearer to the essences and meanings of this as experienced by nurses in Jersey. Further aims have been to consider the implications of these outcomes for practice from this new understanding of the experience of person-centred care and to nurture 'a measure of thoughtfulness and tact in our professions' (Todres, 2007 p. 27) leading to an enriched vision for person-centred care. This could then lead to positive changes in work places for practitioners and for the people with dementia for whom they care, if those responsible for the delivery and redesign of services are also encouraged to take heed of these findings.

This research makes a significant contribution to knowledge by,

- Being amongst the first to demonstrated the value of using six existentials in its data analysis

- Demonstrating that research using an existential hermeneutic phenomenological methodology is accessible for counsellors from its parallels with therapy
- Going against the grain of much descriptive phenomenological research in demonstrating the powerful potential of poetry and metaphor images to uncover the essences and meanings of phenomena and thereby enhancing nursing research and practice.
- Adding to the body of knowledge concerning person-centred dementia care through its focus on the lived experience of this, confirming the findings of other research not using EHP by exposing the considerable rhetoric in the use 'person-centred' to describe care and services.
- Showing that this term, and the models and frameworks associated with it, are not well understood, highlighting therefore the need for more effective training, education and practice development.
- Revealing the need for new support structures for nurses, and
- Revealing the need for better communication throughout the services.

For myself, the more I have considered these outcomes, the more I have come to realise that this 'being touched by' is leading me towards a search for the 'supersolvent' to free Wheelchair Man. However, while this supersolvent is not yet quite 'evident', or 'patent', I believe it is now 'conceivable' from this focus on lived experiences, which Lindseth and Norberg (2004 p. 148) confirm to be a prerequisite for improvements and change. What follows on from this research for me will be formalising this and applying for its 'patent' by pursuing some of my suggestions for further research, possibly beginning with designing a dementia strategy for Jersey. My hope is that, having arrived at almost the last full-stop of this thesis, you will have your own new project, or the seed of one ready to be nurtured, having been 'touched' by what you have read about the lived experiences, essences and meanings of person-centred dementia care.

Chapter 9 now follows. This is the final chapter, my *very* final ‘pulling it all together’ (Finlay, 2011 p. 247) which I have written as a summary of my lived experience of this ‘transformational journey’. Again, for this I have used the lenses of the six existentials of corporeality, relationality, temporality, mood, spatiality and materiality to guide my descriptions and reflection.

## Chapter 9

### The Spring of Future Harvests: My Lived Experience of a Transformational Journey



## Chapter Nine: My Lived Experience of a Transformational Journey

### The Spring of Future Harvests: A Summary of Key Findings from the Research

From wonder, leading to the formation of the research questions and then answering these through the thesis' philosophical grounding and its methodology and methods, this research has revealed that the lived experience of person-centred dementia care for these participants seemed robed in rhetoric. The term is widely used, yet the experience of person-centred care appeared to be an unreachd ideal, limited by ignorance, naivety and rhetoric, with limited training and education, by participants seeing care as a 'job' rather than 'caring' as a way of being, with limited investment in care environments and staffing, and by leaders who did not share visions, support staff well and struggled to communicate effectively. Morale was low, with staff feeling unsupported and some exhibiting limited pride in their work. Further to this there appeared to be no evidence of the application of any models or frameworks for person-centred practice, an apparent tension between a residual medical model of practice yet with this being termed person-centred.

I believe these outcomes point towards the need for the further research as I have outlined in Chapter 8. My immediate response will be to draw together a team of 'champions' of person-centred care to prepare (in line with Alzheimer Europe's Glasgow Declaration, 2014) a Dementia Strategy for Jersey, with the aim of promoting a commitment to a shared vision for care between our government, H&SS executives and managers, local care home managers and those managing care within the community, and from this I believe further direction will become evident.



This will be challenging work, but through the process of this research the need to prioritize this has become very apparent to me and through the transformational journey of it, I believe I have developed and honed the skills, and confidence necessary for this task. The following is a summary of this journey which has led me to this point.

## My Lived Experience of this Transformational Journey

### An Introduction

#### The Spring of Future Harvests

When the harvest is done,  
And it seems  
All life has been spun  
From the tree,  
The ground  
Beneath, with open arms  
Welcomes in its embrace  
The seed,  
To rest, shrouded a while  
In the dark, humus of life  
Where nature  
Broods over it,  
Nurturing,  
New life creating,  
Awaiting  
Something new  
To grow.

Approaching this last part of the thesis felt a little like I imagine a marathon runner must feel when, rounding a bend in the road after many long miles of endurance, sweat and perhaps knowing very well the futility of attempting to ignore those painful blisters, she sees the finishing tape in sight.

I held onto this image and while it was very true to some extent for me, I also had a growing sense of this not being quite right, of it not being the whole story, but that in a way, my race might also only just be beginning. Once this new image had taken hold, I knew this was the reality for the runner. This

prompted me to look again at the illustrations I had designed to begin the first eight chapters of this thesis and from this re-view begun to envisaged another for this chapter, which was not what I initially had in mind for its title page. This new image is of a seed from the original tree, buried deeply in the earth. It is full up to capacity with potential for new growth, so much so that its shell is ready to burst. Through its porous membrane it is being enriched by warmed earth nutrients and gentle rain. This linked the idea of the marathon runner at both the end of one race and the start of another, with the seed and the tree, and describes my position as I have outlined at the end of the summary section above.

The final pages of this thesis will be a summary of my lived experiences of this race, the epistemological process of running it that has taught me so much and led to significant personal development, growth and change and which has led to ontological changes in my being, represented now by the new seed. To facilitate this summarising and to focus my reflections, I have chosen, once again, to use the lenses of the six existentials of corporeality, relationality, temporality, mood, spatiality and materiality. Inevitably these categories will merge and intertwine and the location of some content may seem debatable, but the reflections should speak for themselves.

### Corporeality

Because of having been so emotionally and physically drained at times and having to rely on ageing stamina and finely focussed commitment to persevere, my body certainly feels three years older since formally beginning this project. But, the 'me' who 'is my body' (Merleau-Ponty, 1945-1962; 1964/1968) feels thirty years 'more'. The 'more' is difficult to quantify and even qualify, but incorporates feeling more grounded, knowing where I am standing in the world, even more flesh-of-the-world (Merleau-Ponty, 1964/1968 pp. 248-251) and more willing to travel unknown paths with more wisdom and confidence. This is a good feeling but leaves me wishing that this had come my way thirty years ago, and not just three. I can now wander

and wonder at peace, question, not shying away from wrestling with concepts I would have run a mile from three years ago. At times my brain has felt racked by these, and then later, as though it was being bathed in nectar as I was able to crack some of these difficult ideas. I now love to read, to reflect, to engage with others in sharing their passion for their subjects and to really be more embodied in the whole process of these things, so much so that I feel I almost launch into them without so much of the British restraint I once knew. I am more physically present within situations (Varela et al., 1992) a feeling of '*inhabit*(ing) space and time' (Merleau-Ponty, 1945/1962 p. 139) as my body, with an increased sense of being at home 'of "homecoming" – or ontological familiarity' (Hansen, 2010 p. 172) and of belonging.

I have come to know this research, not as a distant thing or something that could be left on a shelf or 'in' my computer when I switch it off each day, but instead I feel I have 'embodied the work' (Romanyshyn, 2014 p. 351) and been 'pulled into' it and 'lived' it (Hansen, 2010 p. 164) so that it is always where I am and has certainly changed me from the inside out and the outside in.

Another aspect that relates to corporeality is the sense that my body now seems to have a new voice with which to speak. It is my,

'*own* authentic voice amidst the choir of the voices of the scientific knowledge of yesterday... the voices of the educational rules, evaluations and systems.' (Hansen, p. 163)

This new voice undoubtedly 'broke' through from wonder, the 'prelude for philosophizing' and 'the leading voice to the end' (Ibid. p. 172) which has been the constant inspiration within this project, sustaining my openness to its limitless possibilities. The voice changes were subtle, almost unperceivable in the process, but are a sure reality for me now as I am getting used to these bodily signs of progression from naïve researcher to

one with some more maturity who has certainly been ‘changed by the work’ (Romanyshyn, 2013 p. 351).

This voice which speaks from my body, with its clear accent and subtle tones, is also the voice of my body which has, through this project, received more attention than the ‘lip-service’ I feel I had given it in the past. I knew the theory of the ‘felt sense of the body’, ‘Gendlin’s (1972) ‘philosophy of entry into the implicit’ (Galvin and Todres, 2009 p. 310) via the body, and used it in my practice as a ‘tool’ for enlightenment, but before embarking on this project, I had not allowed it so much free speech and liberty. I hope now, as an outcome of this project, I will never silence or gag it again but allow this ‘body based hermeneutics’ (Ibid.) its place.

### Relationality

‘You think the only people who are people  
Are the people who look and think like you  
But if you walk the footsteps of a stranger  
You’ll learn things you never knew you never knew’.  
(Colours of the Wind. *Pocahontas*. Disney, 1995. Appendix I)

I have always loved this song from the film *Pocahontas* primarily because of Pocahontas’ passionate belief in our shared humanity, and have included it here because I now know, even more deeply, of the truths it contains. In Chapter 2, I addressed my beliefs in the equality of all humanity, each being made from the same ‘earth’ (Runcorn, 2001) as ‘universal flesh’ (Merleau-Ponty, 1964/1968 p. 137) and of my welcome of diversity, and balanced this with my belief in the alterity and asymmetry of the Other who could never be fully known to me (Lévinas, 1961/1969; 1998/2006).

Through the process of this research, from engaging philosophically, by reflection on the question of ‘Who Am I?’ by working reflexively, by my immersion into others’ worlds, and through my lived experience of engaging with others throughout this project, I have come to appreciate even more so, the reality of ‘humanity’s shared DNA’. It is true that there was some sense of

being 'outside' from the 'family' of other researchers and the participants, but much like the experience of Charlie Hamilton I referred to in Chapter 8 as he immersed himself into the world of the people of the Peruvian rainforests, of literally walking in their footsteps, I like him, began to see more similarities than differences. Pocahontas, Hamilton and I experienced this through the transformative power of relating deeply with others, which for us all brought new understanding and a sense of being more closely related to others, of a lessening of our differences and of developing a closer identity with the Other.

In this research, my relating began with, though was not exclusively through, dialogue, which Gadamer described as being a potentially transformative power. He wrote that,

‘To reach an understanding in a dialogue is not merely a matter of putting oneself forward and successfully asserting one’s own point of view, but being transformed into a communion in which we do not remain what we were.’ (Gadamer, 1960 p. 387)

Through my work as a counsellor I have often experienced exactly this, of not only the other person being changed through the therapeutic relationship, but of myself being changed too. I love Gadamer’s use of the word ‘communion’ and think he chose this because of its richness, hinting at being more transcendent and metaphysical, incorporating the inter-corporeality that I have experienced in counselling and now as a researcher. I describe these ‘communions’ as having been meeting ‘places’ ‘soul to soul’, in which I understand ‘soul’, not to be something ethereal or detached from the body, but ‘soul’ being a richer term for the person who *is*. In a way too, this ‘communion’ is on-going, even now after completing the fieldwork and as I draw near to completing this thesis, because this communion was, and remains, so much ‘more’ than the meeting of minds, or the sharing of dialogue for the purpose of this research and ‘more’ than an analysis of the findings. It was about embodied relational presence with Others and continues to be so within the words of this thesis and within me.

Working at relational depth in counselling, though rewarding, is never easy, but I had not expected to be so taxed, both physically and emotionally as I was during this project. This was because I knew there was likely to be only one interview with each participant, and that these were unlikely to be no more than a few hours long. I did not expect that I would feel so drawn back into the relationships each time I picked up the transcripts, feeling as though I was in the presence of the person again and with the same weight of responsibility as I feel when I am actually in the room with someone sharing issues with me that are deeply important to them. At these times the participants' presence through the transcripts engaged all of me, body, heart, senses, and mind, entwined in this meeting. It was through the interviews and these further 'meetings' that I got the sense of a deepening relationship and thus learnt more of each person and their experiences. There was certainly no sense of this being just thoughts and words meeting together in my study.

I will end this section concerning relationality now by quoting McCurdy (1998) who Sabat also chose to quote in the final page of a book he co-edited with Hughes and Louw (Hughes et al., 2006 p. 300). Although he writes concerning relationships between people with dementia and caregivers, I am ending with this because it develops Gadamer's ideas and includes those of Vanier (1992, 1999, 2005) who also expresses what I am more convinced of than ever from this project, of my own belief in the beautiful affect of the relational as a means of grace. He says that,

'the awareness of a deeply shared humanity...might permit the caregiver and (nursing home) resident to become the means of grace (Niebuhr, 1963) to each other.'  
(McCurdy, 1998 in Hughes et al., 2006 p. 300)

## Temporality

When reflecting on temporality I found that I just had to begin with Merleau-Ponty's ideas of, time arising 'from *my* relation to things' (Merleau-Ponty, 1945/1962 p. 412) and that the 'past and the future spring forth when I reach out towards them' (Merleau-Ponty, 1945/1962 p. 421). This has certainly been my lived experience of time while undertaking this project. I could define present time in terms of the second my finger hits my keyboard for this word, but more usually now my present time is DPhD (during PhD time) a distinct period of three plus years which has arisen from my 'relation to' being a PhD student. This is a marked period of defining time, and very distinct from other time because of my subjective relation to my PhD. The past was BPhD (before PhD time), time before this PhD 'sprung' into being, and the future will begin (and become a new present) when one day I have written the last word and successfully defended the hundred thousand or so other words and be known as APhD (after PhD time). Such is the monumental impact of this whole PhD experience on my life. Time has been defined by it.

During this (DPhD) time it has often been the case that people have asked me 'what I do'. When I answer, people listen with interest about my work, but then when I continue by saying that I am also a student, another response is frequently visible in their body language, and is very similar to the response shop assistants show when I use my student card for discounts. Their bodies speak their thoughts so eloquently 'A student at that age?' And perhaps it is strange to be taking on such a task that more usually defines time for people more than a few decades younger than me. This is something with which I have had to wrestle many times, feeling a bit like a defender of the realm of my research in my time. This has not been because of others' attacks upon it, but has sprung from my own insecurities and doubts, not so much about its relevance but for what may or may not follow on as a consequence of it, given that I am not thirty years younger! However, I am confident that although I am finite and this thesis will have its time, its content is pertinent for today and reveals the 'complexity of lived experience' (Galvin and Todres,

2009 p. 308) which has touched me and therefore 'can touch others' (Ibid. p. 309).

Another significant aspect of this time is related to productivity, with reflection's, reflexivity's, creativity's and writing's ability to eat up time with their ferocious appetites. There was never enough of it. It was helpful though that van Manen (1990 p. 8) made reference to the inevitability of there being 'difficulties' in the process of research and writing, describing this as 'toil'. Although his text does not make the source of the quote he uses clear, I believe he is probably reflecting on his own productivity in relation to time (toil) when he writes "And this took that long to write"... "After seven drafts!?" It was encouraging that even he should find such difficulty, but it was also extremely daunting to read about the braking systems and speed restrictions which seemed so inevitable when I was just setting out three years ago. This braking resistance has most certainly been something of my lived experience of temporality throughout. I have toiled at times with what has seemed like drag parachutes behind me, thrust reversers inside me and flaps on my wings, language that van Manen never quite used, but I'm sure would recognise. Other times however have flown by as though I have been borne up on eagles' wings with temporality being an amazing high-flying, high-speed experience. I have learnt to recognise and accept the benefits that both extremes of lived experience can bring.

### Mood

A whole host of mood experiences, or feelings, have accompanied me throughout this project, which have demanded attention along the way and shaped its style and direction. I have felt exposed and cocooned, wounded and healed, expectant and despondent, creative and uninspired, confident and daunted, haunted and enlightened, misunderstood and an inspiration for others, lost and found, intruded upon and welcomed, the need to be defensive and willingly open and critical and accepting. It has been quite a roller-coaster of mood experiences.



Perhaps one of the most significant aspects of the existential 'mood' I have encountered through this project is the impossibility of remaining hidden behind my words or in academic jargon or in facts and figures that could possibly 'speak for themselves'. Research such as this incorporates the researcher as an integral, intertwined person within every word that is written and therefore necessitates the researcher being laid bare. What could have once remained internalised before the research has to be exposed, described, reflected upon and worked with reflexively, becoming externalised, 'fix(ing) thought on paper or the screen' (van Manen, 2014 p. 364) and is therefore in full view of the readers. While there was the sense of being called into this research (Romanyshyn, 2013 p. 348) I know I could nevertheless have proceeded along another path with more camouflaging foliage resulting in less exposure, but, difficult though it has been at times, its congruent fit really was inescapable for me and through this I believe I am beginning to 'speak' more confidently in print.

Alongside this sense of exposure, I have also, for most of the time, been in an expectant mood. This sense of expectation has not always been pleasant because there have been twists and turns along the way which have been accompanied by some sense of impending possible disaster around the blind bends. Perhaps because of the length of the road or the duration of the journey, these have now a sense of familiarity to them. They seem more like fellow travellers who have crossed my path so many times that they are no longer strangers to be feared. Experience has taught me this. So, instead of now greeting them with suspicion, I believe I am now seeing them less as potential disaster or ruin, but perhaps more as positive contributors. Other times this expectant mood has been exciting. Because I am now finding I turn up new nuggets of delightful interest along the way so very frequently, I am beginning to view research much less as a project in hand with obstacles to overcome, but more as a journey of exploration with new places for

wondering which I am confident will lead into new fields for new learning and new growth.

As much as my expectant mood is evident to me, so too is my sense of woundedness alongside this. When I first read of this idea in Romanyshyn's book *The Wounded Researcher* (Romanyshyn, 2013) I could immediately identify with this, though the reality of my own woundedness did not strike me until more recently. This is real to me now because I have learnt from this process, that as much as I would have liked, I have not been able to say all that I have wanted or felt I needed to say. The shadow of the unsaid has haunted my saying (Ibid. p. 6) with my words being limited by my command of English, and the English language itself has not been broad or deep enough for all that anyone needs to say or hear. Words too can be killers, killing meaning and becoming the death of objects, or at best a substitution for them (van Manen, 2014 p. 370-371) as well as helping to illuminate them. Van Manen also took up the idea of the 'absence or void that always echoes in everything' (van Manen, 2006 p. 716) and of the image that is evoked by words being a poor substitute for the real presence of the real thing itself 'which constantly eludes our grasp' and leaves a sense of a haunting presence, or there being more in the dark than the darkness can reveal (Ibid. pp. 716-717). The real problem then which so affected my mood was of knowing that I 'must bring into presence this phenomenon that (could) be represented only in words' (Ibid. p. 718) and yet my words could not say it all. Style being so subjective and interpretation being shadowed by knowledge and beliefs added to this. Even my capacity to listen well was 'hard work because it (was) heart work' (Romanyshyn, 2013 p. 340) and with the weight of my ethical responsibility towards others, to re-present what they had communicated of their experience accurately, my mood felt even heavier at times. At the outset of this project I believed I would be successful in my attempt to find a way of using words well and of saying things that did not 'pin down with facts, exhaust (it) with explanations, or imprison (it) with ideas' (Ibid. p. 10) but I have learnt that I have also needed to let go of the work and

allow it the capacity, from its place of freedom, to take on its own life. With this freeing I have had to accept that the work could potentially become something I had not envisioned for it, to be less than my idea of perfect, and that inevitably there will be, to some extent, a 'veneer of human constructs' (van Manen, 2006 p. 718) positioned over 'the silent whispering of the Real' (Ibid. p. 719). Like any 'parent' this 'letting go' of a less than perfect creation has been harder than I ever imagined, but will become no doubt, part of my growth towards maturity.

At times throughout this research I have experienced a sense of feeling lost in the research, both in an epistemologically-based way of not being confident in what I was doing, and existentially with the lived-experience of mooded lostness and weariness with the project, being uncertain about its path and direction. By staying with this lostness and by embracing the 'lived experience of vulnerability, uncertainty, ungroundedness, and lostness' and trusting myself and circumstances of 'being-in-the-world-of-researching' (Mandic, 2014 p. 171) I have found that these places have reformed themselves from uncomfortable, unwanted guests in my research to become, via the pathway of 'astonishment and disorientation', new realms for wonder, and thus have provided opportunities for seeing things in different ways. I have therefore begun to believe in the strength of feeling weak and of discovery from lostness and gain from loss. Not only this, the writing activity and the call for writing to be a 'complex process of rewriting' (van Manen, 1997 pp. 131-132) have helped me appreciate that,

'Writing is a producing activity. The writer produces the text, but he or she produces more than the text. The writer produces himself or herself. The writer is the product of his or her own product. Writing is a kind of self-making or forming. To write is to measure the depth of things, as well as to come to a sense of one's own depth.'  
(van Manen, 2014 pp. 364-365)

Approaching the completion of this thesis, it is true for me that I now feel I have more confidence in answering the 'Who am I?' question I posed in Chapter 2. This researching and writing project has been a means for me to

get to know myself better and with a clearer sense of my own 'depth'. Undoubtedly the times of mooded lostness, experienced together with times when the sun has been so bright in a cloudless sky making the journey seem more like a relaxing stroll, have done their work in me.

While it was really quite obvious to me that mood feelings colour and shape being, and are therefore an essential human life existential, the process of this research has confirmed for me the absolute necessity of their place in such research. As much as it would have been theoretically easier to have ignored some of these or tried to detach their reality and relocate them in some other space or time, such avoidance for me I now know would be absolutely impossible. They are essential for my authentic epistemological and ontological positions in research.

### Spatiality

When I began to reflect on spatiality in relation to my personal learning and growth, I was struck by the significance place the space in which I write has now taken in my life. It is most certainly 'the special place' about which van Manen writes (van Manen, 2014 p. 358). This tiny space is my sanctuary, my creative space in which I am always entirely alone, but in which I can meet the world. By dwelling in 'the textorium: the virtual space that the words open up' I can again be in the presence of the research participants and be transported to the contexts of the interviews or to the places they have described, or just as easily be in another country if instead of writing I choose to read and get drawn into my latest novel. It is a remarkable space that has the capacity to hold the world within its 6'x7' walls and its discovery and the potential of the space has been provided by this project. Beforehand I never knew I had the world at my fingertips.

Alongside this feeling of immersion into others' worlds from the texts, has been another experience of space that has been less comfortable. This is the experience of being an outsider looking into others' worlds. The research participants are all nurses who belonged in the spaces in which they worked.

While much of my work is office and community based, I do also visit people in these places of work so they are familiar to me, but as a visitor. This perspective was not so clear to me at the outset of this project. Apart from my concerns about the practicalities of the interviews, I felt quite at ease about going into meetings to find the answer to my research questions. I did not feel like an imposter but in truth I felt as though I had some right to be there, asking the questions I was, simply because the participants had all agreed to participate. The growing realisation of my outsider status, feeling as though I was beginning to look through frosted glass and listening with ear-defenders on, though uncomfortable for me, was a surprising means of growth. While I was indeed welcomed by the participants into their worlds, I began to see this welcome as a gift and my appropriate response needed to be gratitude, expressed by respectful holding and tentative, careful use of the gift. I began to imagine this as being like a gift from someone from a remote village in a country I had never visited before, and not knowing what the item was, or even what it was made of. There was mystery in this.

Finally, another perspective on the existential spatiality which has become important to me and which relates to personal growth has been the idea of this research project being a 'temporary shelter' (Romanyshyn, 2013 p. 11). Initially this project filled my horizon and really was all there was or perhaps ever could be in my space. There was no sense of it being 'temporary' and nothing beyond. It was not a building from which I could ever see myself moving or growing out of, and certainly was not one I ever felt I was going to willingly dismantle. But now I am in a place where I am almost ready to move on. I appreciate now that a new road will come into view soon and that this present shelter is just another part of my larger nomadic journey through life. From this present perspective I can look back and see other paths with the remnants of other shelters along the way, and envisage, though not quite see, others ahead that I am confident I will be able to build from the muscle of the experience of this shelter's construction and dismantling. It is good to know that these muscles are strong and have been built up in part by

wondering and wandering, actively learning new ways of accessing information, reading more critically, asking more questions, by more critical reflection, by writing and re-writing and engaging as much as possible with others in the 'ring'.

### Materiality

"You must learn to savour words and language – they can change the world." (spoken by John Keating to his students in *Dead Poets Society*, Touchstone, 1989)

I am including my profound and continuous experience of words throughout this project within this section, and while I know them to be much more than material things only, it is their unmistakable, actual, physical presence all around me, which is my focus here. They cover the notice board in front of me, the mirror above this is obliterated by the ones blue-tacked on to it, my desk is loaded up with them in papers and journals all around me, the shelves behind me are creaking with their weight and it seems that this computer has more words within it (somehow) than there are stars in the sky or the grains of sand on the beach just down my road. Their impact has been immense. This project has taught me how to revel in all of these, how to enjoy them, how to seek direction from them and how to find new ones in new places and written by people I would never before have turned to for such enlightenment. Words have new meanings through my new appreciation of hermeneutics and with them I wonder more, ask more questions and feel more creative with their 'flow' and having 'the power of throwing me in turn toward a signification' that I did not 'possess' before (Merleau-Ponty, 1973 p. 142). I now never read either a book, a journal or from the screen without a pencil in my hand, the two having become inseparable. I need to put my marks on others' words to learn from these.

Writing poetry has become a by-product of all this. Although I had written some poems before, I only ever turned to poetry when other words failed me, and more out of desperation to be 'heard' or 'understood' but only allowed

very few people access to these. What I wrote was deeply personal and private, usually an expression of pain and never about the mundane. I knew therefore, that adopting this research methodology would be risky with its focus on the arts to interpret and communicate lived experiences, essences and meanings which first would need to 'touch' (van Manen, 2014 p. 373) me. It felt at first a bit like going out into the dark to look at the stars, not knowing the extent of the cloud cover, or if I might trip on a path darkened by the absence of moonlight. I took some comfort from Galvin and Todres (2009 p. 314) however as they reassured me that I would be free from 'a form of poetic re-presentation' that required me to 'stick' to the same words as my participants. This offered the freedom I felt I needed to allow my own creative style its space, and my voice some part in the new 'songs' I would be creating to reflect a 'meaningful-world-with-others' (Ibid.). As the project proceeded I learnt that I did not need to keep being reminded of this as a co-creative task, and increasingly welcomed the idea of my poetry and metaphors being reimagined by others, (Romanyshyn, 2013 p. 320) and embraced the idea of them breathing on their own and recreating themselves (Ibid. pp. 336-345). I increasingly relaxed into my place as the researcher and trusted the process and my ability to take hold of words and their ability to take hold of me and that I would, 'sing with all the voices of the mountains' and 'paint with all the colours of the wind'. (Colours of the Wind from *Pocahontas*, Disney, 1995).

Other areas of obvious change for me as a result of this project and related to the way in which I now read, is the way in which I engage more generally in the world. This is as weighty as it sounds. When I watch the television, or listen to music, or follow a political debate, the way in which I am 'entertained' by these is now so different, and even while watching the television there is never a pencil too far away. I know there can be pearls of wisdom and jewels of interest in the most unlikely of places that I just don't want to miss.

## To Summarise My Personal Learning and Growth

This experience for me has been about growth, not only of the thesis itself with that tiny, inconspicuous seed growing into its full form through all these pages, but has also been about my personal growth too which is impacting all aspects of my life, professionally, personally and as a researcher. Following Lewis' guidance to,

‘write about what really interests you, whether real things or imaginary things, and nothing else.’ (from C.S. Lewis' letter to an American schoolgirl, in Hooper, 2007)

I was able, like Skeeter Phelan, the central character of the book *The Help* (Stockett, 2009) to keep my passion for the work alive and for it to reach its completion. She knew about the ‘vox humana’ about which Buber (1957/1974 pp. 234-235) wrote and she, like I, was determined that ‘the busy noise of the hour’ would not be allowed to drown out ‘the essence of the human which has become a voice’ through our writing. For Buber, Phelan and myself this was about a way to ‘peace’ by listening to others’ voices, whether just whispers or melodious song, and helping them to be heard and thus being a source of hope for the world.

Merleau-Ponty wrote that,

‘Genuine philosophy is re-learning to see the world, and in this sense, a story recounted can signify the world with as much “depth” as a treatise in philosophy.’ (Merleau-Ponty, 1956 p. 69)

While this thesis is more than a ‘story’, but maybe not quite the philosophical treatise to which Merleau-Ponty was referring, it has certainly been my aim to write in ‘depth’ and in such a way that readers might be enabled to see the world of person-centred dementia care anew through the lived experiences of the participants. Before this research began it was the seed of wonder that hooked me in and rooted itself in me. Hot on the heels of this was my more urgent questioning and the even more urgent need for these questions to be answered which are now entwined within the leaves of this thesis. But now,



### Looking To The East

Looking to the East  
From which wonder first shed its light,  
A new horizon is now bathed  
In emergent, virgin light, the sun  
Bringing its clarity to a new day,  
Jewelling the landscape of my world,  
Beaming clarity, rainbowing lustre,  
Colouring in my world  
With delight-full hues,  
To awaken the seed,  
To usher into being  
New whispers, new song.

‘But finally, when the text seems done (however incomplete or imperfect) we have to let go of it. From now on it will lead a life of its own. It will constitute a textorium, a space for others to enter - to gaze at what reveals itself.’ (van Manen, 2002 p. 249)

and with this,

‘The ongoing dialogue permits no final conclusion. It would be a poor hermeneutist who thought (s)he could have, or had to have, the last word.’ (Gadamer, 1975/2013 p. 603)

So, whispers and song - linger on...

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## Appendix

*Appendix A: The Creation of Adam (sculpture from Chartres Cathedral, France)*



Cathedral

Who has planned your beauty,  
Your architected glory  
For God above - and me? And,  
Who has watched you grow  
Stone by stone,  
Year by year and  
Wondered at your changing form,  
So mighty, so strong and full  
Of hope to defeat the assaults  
Of any enemy of earth or heaven? And,  
Who has placed those stones  
In worship?  
Or craftsman's pride? And,  
Who has laboured alongside for  
A lifetime of days' light  
To provide for those who built? And  
Who has paid the price  
For such monumental triumph  
Reaching to the sky  
With thirty pieces of silver or  
Golden blood?  
I wonder at your secrets  
Of days  
Held in stone.

They Stood By His Grave

They stood by his grave,  
A father's strength  
In stoic pride,  
In rank and medal honour.  
His pulse by anger raised,  
Synchronized with trumpet call,  
The mighty songs of war  
And the yet more glorious dead.

They stood by his grave,  
Her mutilated heart  
Now emptied, as her mother arms  
Growing hunger to hold  
Her son, even in death.  
His wife no more  
An earthly lover, numbed in all sense  
One flesh as dead as his.

They stood by his grave,  
And his little child, God bless  
His fruit. To fight on  
In wars of his own time?  
Looked into the deep future  
Of darkness and longing,  
Of resurrection and spring?  
With hopeless downcast eyes.

They stood by his grave,  
Together, pride giving way  
To tears flowing onwards  
To some yet distant sea of hope,  
Their rivers uniting  
The living and the dead.  
The tear drenched soil  
His shroud.

Appendix D: Documents relating to the application for ethic approval for this research from Canterbury Christ Church University



DATE of Assessment:	16.12.2013	ASSESSMENT NO:	
Assessed by (Name):	Sian Wareing-Jones	DEPARTMENT code:	
NATURE OF ACTIVITY:	Ph.D. Research	DATE OF ACTIVITY:	
LOCATION:	Jersey C.I.	REVIEW DATE:	

HEALTH AND SAFETY - RISK						
Hazard	Persons at Risk	Current Control Measures	Severity (S)	Likelihood (L)	Risk Rating (S x L)	Action to follow:
The nature of the research and the interview process.	All research participants	Participants will give their full informed consent to participate in research.  All participants will be sent a written participant information sheet giving details of the study and what is expected of them, alongside a consent form. My contact details will be included to give participants the opportunity to discuss their (cont.) participation with me.	1	1	Low	None

Severity (S):	Likelihood of Harm (L):	Risk Rating: (S x L)
Minor injury or illness	1 Very unlikely	1
Moderate injury or illness	2 Unlikely	2
"3 day injury" or illness	3 50 / 50 likelihood	3 5 to 9
Major injury or illness	4 Likely	4 10 to 16 Adequate
Fatality	5 Very likely / certainty	5 17 to 25 High / Unacceptable

No further actions but ensure controls are maintained.  
Look to improve at next review.

Look to improve within specified timescale.

Stop activity immediately and make appropriate improvements.

For Health and Safety advice, go to [www.canterbury.ac.uk/support/health.safety](http://www.canterbury.ac.uk/support/health.safety) or contact [health.safety@canterbury.ac.uk](mailto:health.safety@canterbury.ac.uk)



Hazard	Persons at Risk	Current Control Measures	Severity (S)	Likelihood (L)	Risk Rating (S x L)	Additional Control Measures Required	Revised Risk Rating	Action Sign Off Date/ Responsible Person
Disclosure during the interview that indicates that a participant may be a risk of harm to self or others.	All research participants	Information will be repeated to participants at the start of all interviews to ensure participants understand the process and are happy to proceed.  Only adults over 18 years will be interviewed.  The participants will be informed beforehand that they do not need to disclose anything they do not wish to, but that I will inform relevant authorities if I consider anyone is at risk of harm. I use such contracts in my employment as a counsellor.	1	1	Low	None		

Severity (S):	Likelihood of Harm (L):	Risk Rating: (S x L)	Risk Evaluation:	Action to follow:
Minor injury or illness	1 Very unlikely	1	Low / Acceptable	No further actions but ensure controls are maintained.
Moderate injury or illness	2 Unlikely	2	Medium / Adequate	Look to improve at next review.
"3 day injury" or illness	3 50 / 50 likelihood	3	High / Unacceptable	Look to improve within specified timescale.
Major injury or illness	4 Likely	4	Very High / Unacceptable	Stop activity immediately and make appropriate improvements.
Fatality	5 Very likely / certainty	5		

For Health and Safety advice, go to [www.canterbury.ac.uk/support/health/safety](http://www.canterbury.ac.uk/support/health/safety) or contact [health.safety@canterbury.ac.uk](mailto:health.safety@canterbury.ac.uk)

Hazard	Persons at Risk	Current Control Measures	Severity (S)	Likelihood (L)	Risk Rating (S x L)	Additional Control Measures Required	Revised Risk Rating	Action Sign Off Date/ Responsible Person
As with all research there is the potential for participants to become upset or distressed in sessions.	All research participants	I will ensure that the participants are aware they can stop the interview at any stage. As the researcher I will be immediately available to offer support and will signpost participants to Health and Social Services free counselling service should I feel this to be appropriate.  The participants will be reminded of their right to withdraw consent to continue should they experience difficulties.	1	1	Low	None		
Confidentiality and anonymity	All research participants	Confidentiality and data protection requirements will be set out in the initial information sheet.  All data will be made anonymous	1	1	Low	None		

Severity (S):		Likelihood of Harm (L):		Risk Rating: (S x L)		Risk Evaluation:		Action to follow:	
Minor injury or illness	1	Very unlikely	1	1	1	Low	Acceptable	No further actions but ensure controls are maintained.	
Moderate injury or illness	2	Unlikely	2	2	2	Low	Acceptable	Look to improve at next review.	
"3 day injury" or illness	3	50 / 50 likelihood	3	3	3	Medium	Adequate	Look to improve within specified timescale.	
Major injury or illness	4	Likely	4	4	4	High	Unacceptable	Stop activity immediately and make appropriate improvements.	
Fatality	5	Very likely / certainty	5	5	5	High	Unacceptable	Stop activity immediately and make appropriate improvements.	

For Health and Safety advice, go to [www.canterbury.ac.uk/support/health.safety](http://www.canterbury.ac.uk/support/health.safety) or contact [health.safety@canterbury.ac.uk](mailto:health.safety@canterbury.ac.uk)

Hazard	Persons at Risk	Current Control Measures	Severity (S)	Likelihood (L)	Risk Rating (S x L)	Additional Control Measures Required	Revised Risk Rating	Action Sign Off Date/ Responsible Person
		<p>(cont.) and personal information will be removed which could reveal a person's identity and if required participants can choose not to reveal their names to me.</p> <p>I am the sole researcher and will not be discussing this information with anyone else other than my supervisor. Anonymised data will only ever be available to others.</p> <p>All data will be stored securely at the researcher's premises in a locked cabinet and no named participant information will be stored electronically. All anonymised information will be stored on my sole use, password protected computer.</p>						

Severity (S):	Likelihood of Harm (L):	Risk Rating: (S x L)	Risk Evaluation:	Action to follow:
Minor injury or illness	1 Very unlikely	1	Low / Acceptable	No further actions but ensure controls are maintained.
Moderate injury or illness	2 Unlikely	2	Medium / Adequate	Look to improve at next review.
"3 day injury" or illness	3 50 / 50 likelihood	3	Medium / Adequate	Look to improve within specified timescale.
Major injury or illness	4 Likely	4	High / Tolerable	Stop activity immediately and make appropriate improvements.
Fatality	5 Very likely / certainty	5	Unacceptable	

For Health and Safety advice, go to [www.canterbury.ac.uk/support/health.safety](http://www.canterbury.ac.uk/support/health.safety) or contact [health.safety@canterbury.ac.uk](mailto:health.safety@canterbury.ac.uk)



## INFORMATION FOR PARTICIPANTS

### PERSON-CENTRED DEMENTIA CARE RESEARCH

#### **The Essence and Lived Experience of Person-Centred Dementia Care: A Phenomenological Inquiry With Health Care Professionals Working In Jersey, Channel Islands**

Thank you for contacting me about taking part in a research study. This sheet sets out further information about me and the research study. I would be grateful if you would read it and then consider if you would like to be involved in the study.

I am a Ph.D. student at Canterbury Christ Church University and a Jersey resident. My research interest is in Person-Centred Dementia Care, the model of care used in most hospitals and care homes in Jersey and throughout the UK.

This research necessitates I talk with health care professionals; nurses, care-assistants or health-care assistants to discover something of their experiences at work. The people I want to speak with will need to work in a location where the people being cared for have dementia and the place of work uses Person-Centred care. You will need to be over the age of 18.

Research participants will need to be able to spend about an hour with me, possibly on 2-3 occasions during which time I will ask you to describe for me what various aspects of your work are like for you and I may ask a few questions about your work.

Interviews will be totally confidential. They will be audio recorded but once transcribed, recordings will be deleted. Transcripts will only be seen by me the researcher and will be kept securely until the end of the research process when they will be destroyed. All documentation throughout the whole process will be anonymised and will not contain your name or the name of your work place. You will be able to see a copy of your interview transcript if you wish. The final research thesis will also be anonymised.

Even if you agree to take part in this study you will be able to withdraw from it at any time without giving a reason.

You will be required to sign a consent form prior to the interview. Consent forms will not be attached to other documents or transcripts so this can never be linked together with other anonymised data.

You will be able to ask as many questions as you wish at any stage. If you require further information to assist you in your decision concerning your participation in this research, please do not hesitate to contact me.

Taking part is entirely optional and is not related to your work or Manager in any way.

This research is being carried out independently of The States of Jersey but is being undertaken with the agreement of The States of Jersey.

For further information please contact-  
Sian Wareing-Jones  
Ph.D. Researcher  
Canterbury Christ Church University  
[s.c.wareing-jones521@canterbury.ac.uk](mailto:s.c.wareing-jones521@canterbury.ac.uk)

This research is being supervised by-  
Professor Jan Dewing  
Canterbury Christ Church University  
[jan.dewing@canterbury.ac.uk](mailto:jan.dewing@canterbury.ac.uk)



## QUESTIONING IN THE RESEARCH INTERVIEWS

In hermeneutic phenomenology, the purpose of the interview is to gather accounts of personal life stories as either anecdotes, stories, experiences or incidences and so on.

I will ask the following, general questions to check that the participants fulfil the criteria for the research and that I understand the breadth of their work contexts before moving onto the main body of the interview which will provide the depth of experience needed for this research. The initial questions will be:

1. Where do you work?
2. What is your job title?
3. How long have you been doing this work (or similar work with people with dementia)?
4. What qualifications or training do you have in this field?

Because of the nature of hermeneutic phenomenology it is impossible to state the questions I will ask here in any detail. However, I can share an outline. To begin with questions will be very general, broad and open, for example:

1. How do you come to be doing the work that you do?
2. Can you tell me in your own words what your work caring for people with dementia is like?

This should lead on to questions like,

1. Can you give an example of....?
2. What was this like?
3. What does this mean for you?

The specific wording and focus will come from close, attentive listening and in response to what the research participants themselves bring to these interviews. However, so that I gather in-depth information related to the research questions and so that this material is as close to the lived experiences as possible, I will need to ask the person to think of and tell me about specific instances, or people or events in relation to the place in which they work, time in relation to their work, their relationships at work, of themselves as they work and of their experience of training and support. I will then encourage the research participants to explore these experiences to the fullest, prompting only as necessary. I will probably need to reflect on the interview using hermeneutic processes and then ask participants for another interview(s) to follow up in more detail.

Researcher: Sian Wareing-Jones  
Canterbury Christ Church University  
[s.c.wareing-jones521@canterbury.ac.uk](mailto:s.c.wareing-jones521@canterbury.ac.uk)  
[sianwareing-jones@hotmail.co.uk](mailto:sianwareing-jones@hotmail.co.uk)  
07797769622

This research is being supervised by-  
Professor Jan Dewing.  
Canterbury Christ Church University  
[jan.dewing@canterbury.ac.uk](mailto:jan.dewing@canterbury.ac.uk)



PERSON-CENTRED DEMENTIA CARE RESEARCH  
PARTICIPANTS WANTED FOR PH.D. RESEARCH

I am a Jersey resident, undertaking a Ph.D. research project in the field of Person-Centred Dementia Care and for this I need to recruit people to take part in semi-structured interviews.

Taking part in this research is completely optional.

Confidentiality and anonymity are assured throughout the process.

If you meet the following criteria I would be delighted to hear from you-

- You work in a care-home, nursing-home or hospital with people with dementia
- You are a care assistant, health-care assistant or nurse
- You are over 18

This research is particularly suitable for people who are happy to talk at depth and in detail about things.

Please make initial contact with me via the email address or telephone number below and I will then forward further information about the project to enable you to decide if you wish to participate. Please also call or email if you have any further questions.

I do not work for the States of Jersey. This research is independent of the States but undertaken in agreement with them.

Thank you for your interest in this research

Sian Wareing-Jones

Researcher: Sian Wareing-Jones  
Canterbury Christ Church University  
sianwareing-jones@hotmail.co.uk  
07797769622

This research is being supervised by-  
Professor Jan Dewing.  
Canterbury Christ Church University  
jan.dewing@canterbury.ac.uk

## CONSENT FORM

**Title of Project:** The Essence and Lived Experience of Person-Centred Dementia Care: A Phenomenological Inquiry With Health Care

Professionals

Working In Jersey, Channel Islands.

**Name of Researcher:** Sian C. Wareing-Jones

**Contact details:**

Address:

The Graduate School  
Canterbury Christ Church University  
North Holmes Road  
Canterbury  
Kent  
CT1 1QU

Tel:

01227 782701

Email:

s.c.wareing-jones521@canterbury.ac.uk

Please initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I understand that the interviews will be recorded and transcribed and that this information and any other I may provide will be strictly confidential and will be anonymised.
4. I agree to take part in the above study, that my data can be included in the thesis and in publications and presentations.


-----

Name of Participant

Date

Signature

-----

Researcher

Date

Signature



FACULTY OF HEALTH AND SOCIAL CARE  
FACULTY RESEARCH ETHICS COMMITTEE

DECLARATION

**Project Title: The Essence and Lived Experience of Person-Centred Dementia Care: A Phenomenological Inquiry With Health Care Professionals Working In Jersey, Channel Islands.**

**Project No:**

- The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
- I undertake to conduct this research according to the Research Governance Framework for Health and Social Care and in accordance with University Research Governance procedures.
- If the research is approved, I undertake to adhere to the study protocol without agreed deviation and to comply with any conditions set out in the letter sent by the Faculty REC notifying me of this.
- I undertake to inform the Faculty REC of any changes in the protocol and to seek their agreement and to submit annual progress reports. I am aware of my responsibility to be up to date and comply with the requirements of the law and appropriate guidelines relating to security and confidentiality of participant or other personal data, including the need to register when appropriate with the appropriate Data Protection Officer.
- I understand that research records/data may be subject to inspection for audit purposes if required in future and that research records should be kept securely for five years.
- I understand that personal data about me as a researcher in this application will be held by the Faculty REC and that this will be managed according to the principles established in the Data Protection Act.
- I CONFIRM that, if required by the nature of my study, I have a current CRB Check in place.

**Print Name: Sian C. Wareing-Jones**

**Date: 18<sup>th</sup> December 2014**

*Sian C. Wareing-Jones*



*Appendix E: Letter of approval from the Service Director of Older People's Services, Jersey*

**Community and Social Services**

Administration Block 1  
Overdale, Westmount Road  
St Helier, Jersey, JE1 3UH  
Tel: (01534) 445756  
Fax: (01534) 443093



Mrs Sian Wareing-Jones  
17 Clos Lempriere  
La Rue du Maupertuis  
St Clement  
Jersey  
JE2 6BH

9<sup>th</sup> October 2013

Dear Sian

Apologies for the delay in getting back to you but I have been waiting for a response from the chairman of the ethics committee, but I am aware they have been snowed under with work.

After re reading your PhD proposal, and noting that the proposal does not involve any work with patients, vulnerable people or children and your interactions consist of interviews with consenting adults, I am happy to support your research proposal.

Thank you for keeping me informed, I am pleased your ongoing studies are going well.

Yours sincerely

A handwritten signature in black ink, appearing to read "Ian Dyer".

**Ian Dyer**  
**Service Director, Older People Services**

c.c. Paul McCabe (Ethics Committee)

*Appendix F: Letter of approval from Research Governance Manager,  
Canterbury Christ Church University*



24 February 2014

Ref: 14/FHSC/020

Ms Sian Wareing-Jones  
17 Clos Lempriere  
La Rue du Maupertuis  
St Clement  
Jersey JE2 6BH

Dear Sian

**Project Title: 'The essence of person-centred dementia care: a phenomenological inquiry with health care professionals working in Jersey, Channel Islands.'**

Your application was reviewed by the Faculty of Health and Social Care Research Ethics Committee on 29 January 2014. The Committee agreed that final approval could be given once certain conditions <sup>2</sup> as set out in the Chair of the Committee VHPDLO of 14 February 2014 <sup>2</sup> were met.

The Chair of the Committee is content that these conditions have now been met in full, and I am writing to give formal confirmation that you can commence your research. Any significant change in the question, design or conduct of the study over its course should be notified to the **Research Office**, and may require a new application for ethics approval. You are also required to inform me once your research has been completed and any qualification awarded.

With best wishes for a  
successful project.

Yours sincerely

Roger Bone  
Research Governance  
Manager  
Research Office, Eg21  
Tel: 01227 782940 ext  
3272 (enter at prompt)  
Email:  
[roger.bone@canterbury.ac.uk](mailto:roger.bone@canterbury.ac.uk)

cc: Dr Pat Chung

Writing Up

How do words come?  
As appetite, fatigue, like the rhythm of the seasons  
awaiting an unfolding  
from the calling of the 'more'  
the flesh of the world  
the interwoven body  
Here I am  
flickering sense  
wells in me  
just enough...

The body knows  
delicate murmuring  
sensing of some gentle form  
and then it goes.  
*Unformed yet felt...there is much more than this*  
*much more than this*  
fleetingly,  
vague stirrings echo words, each felt whisper,  
an opening to what is known  
The body knows  
More than this.

(Galvin and Todres, 2009b pp. 312-313, in Prendergast et al., 2009)

*Appendix H: Poem: Caged Bird (Maya Angelou, 2015)*

Caged Bird

A free bird leaps  
on the back of the wind  
and floats downstream  
till the current ends  
and dips his wings  
in the orange sun rays  
and dares to claim the sky.

But a bird that stalks  
down his narrow cage  
can seldom see through  
his bars of rage  
his wings are clipped and  
his feet are tied  
so he opens his throat to sing.

The caged bird sings  
with fearful trill  
of things unknown  
but longed for still  
and his tune is heard  
on the distant hill  
for the caged bird  
sings of freedom.

The free bird thinks of another breeze  
and the trade winds soft through the sighing trees  
and the fat worms waiting on the dawn-bright lawn  
and he names the sky his own.

But a caged bird stands on the grave of dreams  
his shadow shouts on a nightmare scream  
his wings are clipped and his feet are tied  
so he opens his throat to sing.

The caged bird sings  
with a fearful trill  
of things unknown  
but longed for still  
and his tune is heard  
on the distant hill  
for the caged bird  
sings of freedom.

(Maya Angelou, 2015 p. 189)

*Appendix I: Colours of the Wind (Pocahontas, Disney Films)*

You think I am an ignorant savage  
And you've been so many places  
I guess it must be so  
But still I cannot see  
If the savage one is me  
How can there be so much that you don't know  
You don't know...

You think you own whatever land you land on  
The earth is just a dead thing you can claim  
But I know every rock and tree and creature  
Has a life, has a spirit, has a name.

You think the only people who are people  
Are people who look and think like you  
But if you walk in the footsteps of a stranger  
You'll learn things you never knew you never knew

Have you ever heard the wolf cry to the blue corn moon  
Or asked the grinning bobcat why he grinned?  
Can you sing with all the voices of the mountains?  
Can you paint with all the colours of the wind?  
Can you paint with all the colours of the wind?

Come run the hidden pine trails of the forest  
Come taste the sunsweet berries of the earth  
Come roll in the riches all around you  
And for once, never wonder what they're worth

The rainstorm and the river are my brothers  
The heron and the otter are my friends  
And we are all connected to each other  
In a circle, in a hoop that never ends

How high will the sycamore grow?  
If you cut it down you'll never know  
And you'll never hear the wolf cry to the blue corn moon

For whether we are white or copper skinned  
We need to sing with all the voices of the mountains  
We need to paint with all the colours of the wind

You can own the Earth and still  
All you own is earth until  
You can paint with all the colours of the wind.  
(Song from the film *Pocahontas*. 1995. Disney.)

